DOCUMENT RESUME

ED 334 738 EC 300 484

TITLE 1990 Report: A Report to the Governor on the Status of Alaskans Who Experience Developmental Disabilities.

INSTITUTION Alaska Governor's Council for the Handicapped and Gifted, Fairbanks.

PUB DATE 2 Jan 90

NOTE 119p.

PUB TYPE Reports - Research/Technical (143) -- Viewpoints (Opinion/Position Papers, Essays, etc.) (120)

EDRS PRICE MF01/PC05 Plus Postage.

DESCRIPTORS Civil Rights; Compliance (Legal); *Delivery Systems; *Developmental Disabilities; Employment; Federal Legislation; Health Services; Housing; Income; Independent Living; Normalization (Handicapped); Participant Satisfaction; Personal Autonomy; Productivity; Public Policy; Rehabilitation; *Social Integration; Social Support Groups; State Programs; State Surveys

IDENTIFIERS *Alaska; *Developmental Disabled Assist Bill of Rights Act

ABSTRACT

This report was prepared in response to Public Law 100-146, the Amendments to the Developmental Disabilities Assistance Act, which requires that information and recommendations be made available concerning public policy to promote independence, productivity, and integration of people with developmental disabilities. Information was gathered via interviews with 281 people with developmental disabilities and their families; two teleconferences with a total of 65 people giving testimony; and public forums held in Bethel, Anchorage, Wasilla, Soldotna, Fairbanks, Kotzebue, and Ketchikan. The first section of the report describes the methodology used; the second section provides accounts of each of the seven public forums; and the third section assembles the facts, critical issues, and recommendations and organizes them into the following issue areas: civil rights, education, employment, health care, housing, income, individual and family supports, and systems issues. (JDD)

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ALASKA
GOVERNOR'S COUNCIL FOR THE
HANDICAPPED AND GIFTED

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1990 REPORT

A REPORT TO THE GOVERNOR ON THE STATUS OF ALASKANS WHO EXPERIENCE DEVELOPMENTAL DISABILITIES

JANUARY 1990

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January 2, 1990

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Executive Summary

When Congress enacted P.L. 100-146, the Amendments to the Developmental Disabilities Assistance Act and Bill of Rights, they mandated that each state's developmental disabilities council undertake a public planning process that included a consumer satisfaction survey, policy analysis, and public forums. On January 1, 1990, reports will be submitted to the governors and legislators of each state and territory with information and recommendations resulting from this process.

Alaska has a history of supporting similar planning efforts, including groups such as the Governor's Interim Commission on Children and Youth, The Interim Health Commission, and the Interagency Coordinating Committee, which is planning for implementation of P.L. 99-457.

In the past year and a half, more than 600 Alaskans provided information and recommendations for this report through the consumer satisfaction survey, teleconferences and public forums. The majority of those involved were consumers and families or guardians of people who experience disabilities. They expressed strong support for the values of independence, productivity and integration emphasized by P.L. 100-146.

The federal legislation emphasized the change in attitudes towards people who experience disabilities that has taken place in the past ten years. Consumers, parents, service providers and state agency representatives echoed these new ideas. Consumers want programs that are family focused, provide for consumer involvement, and support local control and innovation.

During the past year and a half of gathering information and testimony, a few critical issues were raised on a regular basis. The major issues are listed below. More detailed information on each issue can be found throughout this report. Major issues were:

1. **MEDICAID**

   Alaska's Meicaid system is clearly not working for many people who experience developmental disabilities. The state's program takes advantage of few of the options or waivers that would benefit consumers. There are currently a number of Medicaid reform bills before Congress which would allow states to use Medicaid funds for community based programs. It is critical that the state explore the options and waivers available and determine which ones will best meet the current and

future needs of Alaskans with developmental disabilities.

2. SYSTEMS ISSUES

Administrative structure of state agencies

Alaskans with developmental disabilties take advantage of a wide range of services and programs provided by a number of departments in state government. Services often lack continuity and consumers are required to repeatedly establish their eligiblity and need for services. Interdepartmental and interdivisional procedures should be improved or streamlined to make the system of services more responsive to the needs of the consumer. This will be especially important as the Mental Health Trust settlement framework is determined.

Long-term financial support for services

The system of services available to Alaskans who experience developmental disabilities has shifted from an institutionally based system of services to one that is community based. Parents and consumers are extremely concerned about the state's long-term commitment to these services and the annual process of allocating funds. Many called for an entitlement program for basic services for people with developmental disabilities and their families.

State definition of developmental disabilities

The current state definition of "developmental disability" includes only those who experience mental retardation, cerebral palsy, autism and epilepsy. The federal definition includes all those with significant functional limitations, regardless of type of disability. The state definition should be expanded to be comparable to the federal definition so that all those with similar needs are eligible for services.

Transition planning

When a young person with developmental disabilities finishes high school at age twenty-two, he or she is often left with nothing to do but sit at home, with none of the educational, vocational or therapy

services they had available while in school. Planning for the student's transition from school should begin by the time the student is fourteen. In addition, community residential and vocational opportunities must be expanded to provide students with options once they graduate from high school.

Waiting lists

There are 320 people on the Division of Mental Health and Developmental Disabilities (DMHDD) waiting list. This includes people waiting for residential, vocational and in-home services. In addition to the need for new programs and services, consumers and parents also need to have a reliable estimate of how long they will have to wait if a service is not immediately available.

3. REGIONALIZATION OF SERVICES

People with developmental disabilities living in the state's rural areas, especially in areas not accessible by highway, have few services available to them. Respite programs are just beginning in Kotzebue, Nome, Bethel and Dillingham and even this minimum level of service is not available in the smaller villages in those regions. Consumers and their families living in the state's less populated regions want services but said that the services must support community values and lifestyles and provide for community and individual empowerment. This will mean that the state must develop new ways of providing services and modify the funding agency relationship with local service providers in these areas to provide greater flexibility in how services are delivered.

The planning process that resulted in this report provided a wealth of information and is the basis for the Governor's Council's Legislative Priorities Report and the Council's next three year state plan, which will focus on ways to implement the recommendations of this report.

INTRODUCTION

> "It is in the national interest to offer persons with developmental disabilities the opportunity, to the maximum extent feasible, to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights and responsibilities as citizens" (P.L. 100-146) Developmental Disabilities Assistance and Bill of Rights Act [Sec. 101(a)(8)]

In 1987, Congress amended the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 100-146) and required state developmental disability councils to prepare "1990 Reports". These planning documents were to be based on three information gathering activities;

1. a consumer satisfaction survey,
2. policy analysis of state and federal funding sources for programs for people with disabilities,
3. public forums.

Congress envisioned this process as a means for each state council to solidify its role as advocates for public policy change.

The purpose of the 1990 Report is to have an impact on public policy by making information and recommendations available to governors, legislatures and to Congress. One of the most important goals of the "1990 Report" is to demonstrate how public policy can change to support the full citizenship of people with developmental disabilities. In the Act, Congress specified that public policy should promote three things for people with developmental disabilities:

* **Independence**: the ability to make choices and to exercise control over one's life;
* **Productivity**: the opportunity to work and make a contribution, and;
* **Integration**: the participation in the richness of life within society, not apart not from it.

During January 1990, "1990 Reports" will be submitted to the governors and legislatures in every state and territory. Congress will receive a national summary for review by April 15, 1990.

The development of the Alaska "1990 Report" began during the fall of 1988 with the Consumer Satisfaction Survey. Since then, more than 600 Alaskans have provided energy, information, criticism, and recommendations to this report.

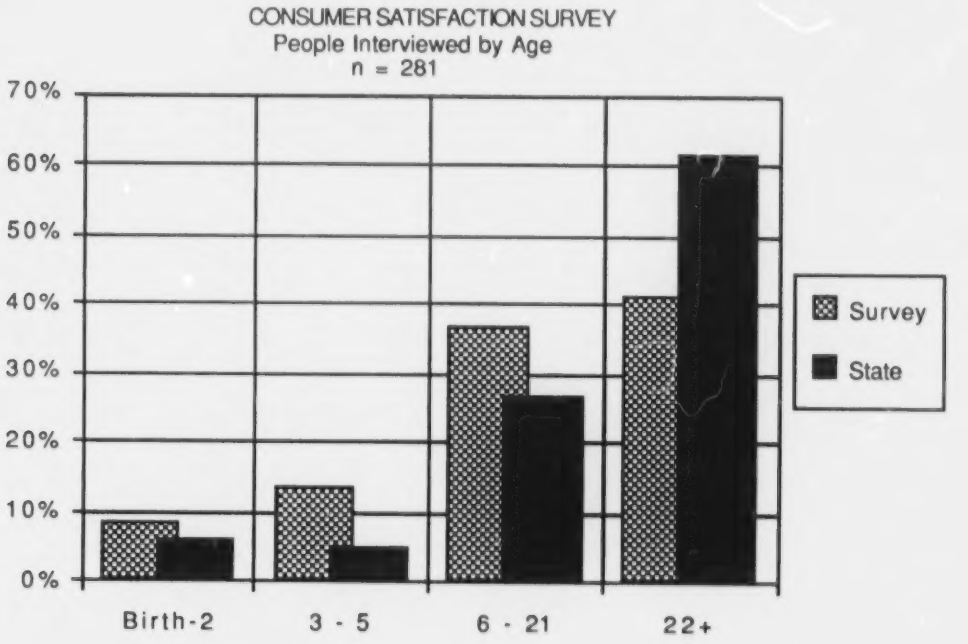
The Governor's Council modified the federal process slightly to add two statewide teleconferences over the Legislative Information Network to gather information from consumers, service providers and advocates from throughout the state. The Council used the forums as an opportunity to encourage community action on issues important to local people with disabilities and their families. Further discussion of what happened at these teleconferences and forums can be found in the following chapters.

CONSUMER SATISFACTION SURVEY

States and territories were required to conduct a survey of people with developmental disabilities and their families to assess their views on services and to determine the impact of services on their independence, productivity and integration into the community.

The Temple University Developmental Disabilities Center, under contract to the National Association of Developmental Disability Councils, designed a survey instrument for use by states and territories so that the information could be compared across states. Nationally, approximately 10,000 people with developmental disabilities and their families were interviewed.

In Alaska, 281 people were interviewed for the consumer satisfaction survey. Because little is known about the needs of people living in rural areas, concerted efforts were made to identify people with developmental disabilities in the state's more remote regions.



A great deal of information was gathered and will provide the basis for service system planning for years to come. It will

take at least another year to fully analyze all of the information. Much of the information in the facts sections of the following chapters is based on information gathered as part of the survey.

The percentages of people interviewed by primary disability were:

Autism	4.0%
Blind/Visually Impaired	2.0%
Cerebral Palsy	15.3%
Deaf/Hearing Impaired	3.2%
Emotional Disability	4.8%
Epilepsy	1.6%
Head Injury	2.0%
Mental Retardation	48.6%
Multiple Sclerosis	1.2%
Muscular Dystrophy	0.8%
Orthopedic Impairment	1.2%
Speech/Language Impairment	0.4%
Spina Bifida	1.2%
Spinal Cord Injury	0.4%
Other Neurological Impairment	2.8%
Other	10.4%

Consumers were asked about how they felt about the services they were receiving. Not surprisingly, people living in urban areas had more experience with programs, especially programs such as vocational rehabilitation, independent living centers, state developmental disability programs and HUD supported housing programs. The programs with which people were the most satisfied (based on the percentage of people who were satisfied or very satisfied) were:

1. Group Homes and Apartments (for 1-5 people)
2. Home Health Aide/Visiting Nurse Programs
3. Job Placement Services
4. Family Care (Foster/Shared Care)
5. Payment/Provision of Medication
6. Special Class in a Regular School (Educational Setting)
7. Medicaid for Medical Care
8. Income Assistance (SSI)
9. Dental Services
10. General Medical Services

All of the people living in small group home or apartment programs said that they were very satisfied with their living situation. Foster and shared care also rated very high among those interviewed. Satisfaction with residential settings decreases as the number of residents increases.

Most of the other services and supports listed are generic services which are available to all Alaskans who qualify and not limited to those who experience disabilities. Because of Alaska's size and small population, there are fewer "specialized" services for people with disabilities than might be found in larger states. It is apparent that the generic services listed above (home health aide/visiting nurse programs, job placement services, payment/provision of medication, Medicaid for medical care, income assistance, dental services and general medical services) are meeting the needs of Alaskans who experience disabilities.

Consumers were also asked about the programs with which they were the least satisfied. These were:

1. Companion/Friend Advocate Programs
2. Family Support Groups
3. Architectural Modifications
4. Child Day Care
5. Family Counseling
6. Mental Health Services
7. Summer School Programs
8. Financial Management
9. Behavior Management

The primary reason most consumers said they were dissatisfied with these services and supports was that they were not receiving enough. This was true for all of the services listed above except architectural modifications and child day care, which consumers said were too expensive.

In the final section of the survey, consumers were asked to describe their ideal support system. The services and supports most often mentioned were:

1. Income Assistance
2. Speech/Language Therapy
3. Health Insurance
4. Case Management
5. Transportation for Leisure Activities
6. Physical Therapy
7. Summer School Programs
8. Occupational Therapy
9. Vocational Training Services
10. Employment Services (Job Coach)

Consumers reported that independence, productivity and integration were important. Approximately 10% said that they were totally independent but 43% said that being independent is very important. Consumer also reported that less than 10% were very productive and 46% said that being productive is very important. More than 16% of those surveyed said that

they were totally integrated into their communities. Almost 60% of those surveyed said that it is very important to be integrated. Independence, productivity and integration are obviously goals for many Alaskans who experience disabilities.

The Governor's Council for the Handicapped and Gifted uses the Levels of Care concept in service system planning. This planning method was developed by the Department of Health and Social Services during the 1970's and utilizes a regional approach that emphasizes the relationships between communities. Communities are classified in the following manner:

Level I	Village (such as Kiana, St. George, Klawock, Atmautluak, Holy Cross, Wainwright)
Level II	Subregional Center (such as Unalakleet, Delta Junction, Toksook Bay, Iliamna, Craig)
Level III	Regional Center (such as Barrow, Kotzebue, Nome, Bethel, Dillingham, Valdez, Juneau, Sitka, Kenai)
Level IV	Urban Center (Fairbanks and Anchorage)
Level V	Metropolis (Seattle)
Other	Usually community clusters, military bases, work sites, and schools

The most interesting information that has come from the survey resulted from analyzing the data based on the Level of Community where the consumer lived. There are striking differences in how consumers feel about the value of integration into their community.

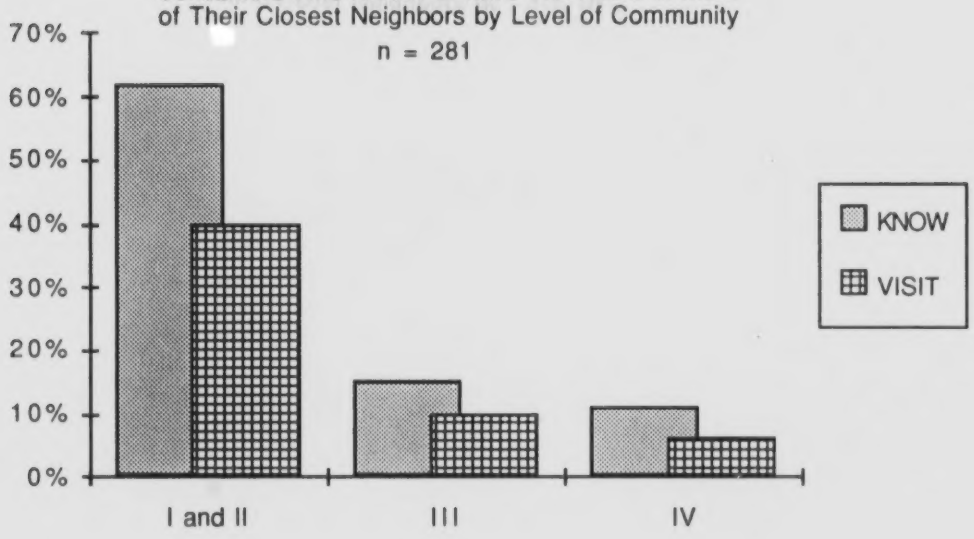
Overall, consumers in Alaska said that integration was the most important of the three values expressed in the federal legislation. In Alaska, young children were the most integrated into the communities and adults the least.

People living in small (Level I or Level II) report being more integrated than those living in the state's largest communities. Although they report going to concerts, malls, restaurants and recreational activities less often than people in larger communities, people living in small communities see friends more often and have more friends who are non-disabled. They also know more of their neighbors and have more contact with them.

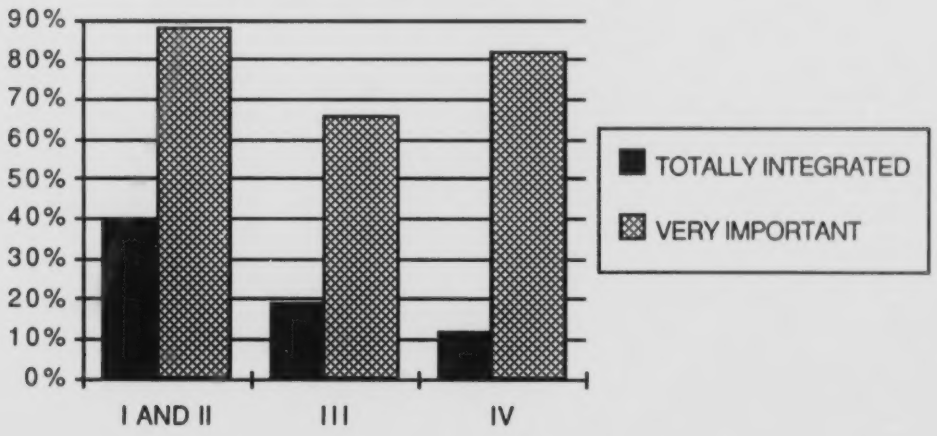
COMMUNITY INTEGRATION

Consumers Who KNOW or have VISITED 6 or More of Their Closest Neighbors by Level of Community

n = 281



COMMUNITY INTEGRATION



COMSUMERS WHO FEEL THEY ARE TOTALLY INTEGRATED OR THAT IT IS VERY IMPORTANT TO BE INTEGRATED BY LEVEL OR COMMUNITY

There are currently few formal services or supports for people who experience disabilities in Level I and II communities. But people living in these small communities have a greater sense of being a part of their community than those living in larger places. As the service system expands to meet the needs of those living in the state's more rural areas, it is essential that the services be individually planned and based on the strengths of each community, as well as, the individual.

POLICY ANALYSIS

Congress required that in completing the "1990 Report", each state conduct a comprehensive review and analysis of the eligibility for services for people who experience disabilities, the scope and effectiveness of those services, and an examination of whether the services promote independence, productivity and integration into the community.

The Governor's Council asked agencies that fund programs or provide direct services to consumers to provide statutes, laws and regulations pertaining to their programs.

Alaska has fewer specialized services for people who experience disabilities than many other states. In order to gain a clear understanding of the supports used by Alaskans, generic service providers, such as the Division of Family and Youth Services, were also asked to provide information.

Each agency was also asked the following questions:

1. Do you serve people who experience developmental disabilities?

2. In F88, what were the
   - total number of people receiving services,
   - actual or estimated number of people with developmental disabilities served,
   - total federal expenditures,
   - total state expenditures,
   - total local expenditures,
   - estimated % of federal/state/local funds expended for people with developmental disabilities?

3. Are services available throughout the state? Where are they not available?

4. What are the eligibility criteria for services? How are services provided?

5. Are the services provided intended to increase the independence, productivity and integration of the person with developmental disabilities? What are the goals of the service provided?

Information was solicited from federal, state and local government agencies that fund services for people who experience disabilities. These agencies fund or provide education, employment and job training, housing, transportation, child protective services and child care, and public health services.

The policy analysis was greatly assisted by the National Association of Developmental Councils, which contracted for the development of technical bulletins that compiled national information on expenditures by program and program characteristics by state. This information was extremely useful in comparing how federal programs are utilized in Alaska, as compared to other states.

A great deal of information was reviewed. Much of this information is found in the issues chapters of this report. Two issues, in particular, are worth noting here:

1. **MEDICAID**

Alaska is one of the most conservative states in the use of Medicaid in the country. In fact, Wyoming and Alaska are the only two states that do not have any type of waiver or use a categorically needy option.

Medicaid waivers allow states to finance certain non-institutional services with Medicaid funding. A state must apply for waiver services but is allowed considerable flexibility, as long as the proposed services cost no more than the corresponding institutional services.

States may also chose to offer any of 32 optional services in the state Medicaid program. Options that are especially important to people who experience disabilities are case management, personal care attendant services, and clinic or rehabilitation services. Another option of growing interest nationally is the extension of categorical eligibility for Medicaid services to children with disabilities who might otherwise be institutionalized. Under this option, children can receive Medicaid funded, home-based services, regardless of their parent's income. Options must be approved by the state legislature.

Because Medicaid plays such an important role in funding services in Alaska, there is a strong institutional bias in services available to Alaskans who experience disabilities. There are currently a number of Medicaid reform bills before Congress which would allow states to use Medicaid funding for community based programs. If this legislation passes, the federal share of programs will be frozen. This means that the state will continue to pay 100% of the costs of these programs.

2. ELIGIBILITY FOR SERVICES

There is a wide range range of eligibility criteria for programs serving people who experience disabilities. Some programs use categorical definitions, serving only those who experience specific kinds of disabilities. Other programs provide services based on the individual's level of functioning and need for service. A few use a combination of both methods. It is not difficult to see how confusing the "service system" can be to someone trying to navigate through it.

It can be especially confusing relating to age. As a person ages, the services and supports they receive change. A child is eligible for medical services, such as the Handicapped Children's Program, that are not available to an adult. Adults also do not have access to therapy services that children receive as part of special education.

Another area of confusion is that some services, such as special education, are entitlement programs. A child is guaranteed these services as long as they meet eligibility criteria. Once a child finishes school, the state is no longer required to provide services.

TELECONFERENCES

Two statewide teleconferences were held to gather information from throughout the state, particularly from communities where public forums were not being held. The teleconferences were held over the state's Legislative Information Offices teleconferencing system.

The October 25, 1989 teleconference was sponsored by Representative Mark Boyer from Fairbanks. Fourteen Legislative Information Office sites (Anchorage, Fairbanks, Bethel, Delta Junction, Dillingham, Juneau, Soldotna, Ketchikan, Kodiak, Kotzebue, Mat-Su, Nome, Sitka and Valdez) were a part of the teleconference with an off-network site added in Kake.

Of the eighty-five (85) people attending the teleconference at sites throughout the state, forty-five gave testimony. Included in the attendees were three state legislators and aides representing five other legislators.

Five people addressed the **institutional bias of the current service system and the difficulty they encounter in acquiring services and supports for family members who are living at home.** A father from the Kenai Peninsula noted that "...if you are willing to put your child in foster care or just give him up to an institution, well, then he qualifies for everything under the sun."

Another often mentioned issue was **the Division of Mental Health and Developmental Disabilities (DMHDD) waiting list. Ten people talked about the need for new residential, vocational and respite services** in their areas and what it means when those services are not provided. A mother from Anchorage encouraged all those listening to remember, "...when they look at numbers on waiting lists that these are not numbers, these are people. It's everyday quality of life that is suffering."

Five parents with young adults about to leave school discussed the **need for transition planning in the schools and for work programs to be ready when the students graduate.** With the number of people currently in the DMHDD waiting list, many young adults finishing high school are spending years at home waiting for a chance at employment.

Consumer empowerment and the **need for choices was addressed by four participants.**

Other issues discussed were;

- in personal care and attendant services, the lack of services for people who are not Medicaid eligible (3) the need for program administrative changes (3), and the lack of choice allowed the consumer in the current Medicaid funded program (2);

- the need for increased sign language interpreter services in "treatment" programs such as A.A., other drug and alcohol programs and in prison programs (3);

- the need for closed captioning for locally produced news and documentary programs (3),

- the lack of parent support groups in most parts of the state (5),

- the need for support and passage of the Americans with Disabilities Act,

- the lack of early intervention services in some areas and the need for more teachers in most programs (3), and

- the importance of respite services to families and the need for additional hours of services (4)..

The second teleconference was held on November 16, 1989 and was sponsored by Representative Johnny Ellis of Anchorage. The sites included were Anchorage, Fairbanks, Barrow, Bethel, Nome, Kotzebue, Dillingham, Kodiak, Soldotna, Mat-Su, Valdez, Juneau, Sitka with one parent from Shishmaref testifying by telephone.

Approximately 40 people attended the second teleconference with 20 providing testimony. Many of the issues that were addressed during the first teleconference were reiterated by those testifying at this teleconference.

Other issues addressed were the lack of accessibility of Alaska state parks, the need for a state Affirmative Action

statement for people who experience disabilities, and the general lack of service in rural areas.

A parent from Anchorage asked those listening, "Do we, as Alaskans, wish to be models for the rest of nation or do we wish to continue to play catch-up and learn from other states which in no way have the resources, the expertise and the money at their disposal that Alaska has?"

PUBLIC FORUMS

In P.L. 100-146, Congress required that each state developmental disabilities council hold public forums to gather input from consumers and other interested citizens for the 1990 Report.

The Governor's Council sponsored forums in Bethel, Anchorage, Wasilla, Soldotna, Fairbanks, Kotzebue, and Ketchikan. Community agencies in each community were awarded $2500 to plan and support their forum. The purpose of the forums was to encourage community action, as well as, gather information.

The Governor's Council contracted with the Center for Community in Sitka for facilitation of the Public Forums. Bruce Anderson and Gina Gross traveled throughout the state over a three week period in November, 1989, facilitating community meetings and assisting work groups of consumers, parents and providers to organize small, locally determined, projects. Where possible, the Governor's Council will support communities with follow-up funding for these projects.

Each community, except Fairbanks, identified activities that they could take action on after the forum. The planning group in Fairbanks will be meeting in January to plan their activities. Some of the activities identified were:

Bethel - The group decided to begin laying the groundwork for informal supports for parents in Akiachak, where they hope to make parent support an integral part of village life.

Anchorage - The group will work with employers to assist them in developing methods of training and supervision of people in supported employment by other employees at the work site, rather than depending on the Division of Vocational Rehabilitation or other social service agencies for support.

Wasilla - Consumers will start a People First chapter.

Soldotna - The group of parents will work with the Kenai Borough School District to develop a resource center which will provide information, be a focus point for linking parents, provide equipment, and do public awareness and political advocacy.

Kotzebue - The focus of this forum was different than any of the others. It focused on storytelling as a means of understanding the strengths and needs of the people and villages of Northwest Alaska. The most likely future activity will be to have another forum to further explore these issues and to begin to discuss ways to support communities and individuals in culturally appropriate and non-disruptive ways.

Ketchikan - The group will form a parent advisory council to advise the school board, administration and staff of the school district.

The full forum reports from each community are included in the following sections.

BETHEL

Wednesday, November 1, 1989 1:00 - 5:00 p.m.
Thursday, November 2, 1989 9:00 - 12:00 Noon

Meeting Structure and Attendance

There were approximately 40 participants, including about 10 parents from nearby villages, several more parents from Bethel, and several professionals, including a Division of Vocational Rehabilitation (DVR) administrator, special education director, and community services (developmental disabilities) staff. Following introductions, the group broke down into three groups to enhance the participation of parents. Each group included both parents and social services professionals. Before beginning the forum, there was a meeting with the facilitators and staff members from Bethel Community Services, the local agency which planned the forum. The result of this meeting was a list of questions that were intended to provide an initial start for the discussions at the forum. Discussion diverted from these questions to accommodate the interests of participants.

Forum Purpose

The purpose of the Bethel Community Forum was to gather information from participants in the theme areas of: transition, what kinds of support it would take to keep a person with a disability in their home community, what it takes to have a person with a disability be an accepted part of village life, what village people would like to see added to school curriculums to enhance a student in participating in village life, and what supports families need to support a person with a disability. The second day of the forum was intended to condense the issues down and to have a core group pick a specific issue they would like to focus on, and organize themselves for action after the forum was over.

Community Action Plan Outcomes

The primary issue that was identified by this group was the need for parent support in rural and remote areas. There were three outcomes of the meeting, as agreed by participants, at the end of the second day:

1. The group came to a consensus that helping to make parent support an integral part of village life was the most important task. Initial groundwork will be done by Bethel Community Services in building informal supports

in Akiachak. There were interested persons from Akiachak at the Forum meeting who agreed it was a needed support in their village, and the community seemed ready to begin. Participants to be included in the planning work are:

-parents and family members
-church/elders
-local government and village council
-health aides
-special education aides and teachers
-parents from other villages
-parent-trainers
-Division of Vocational Rehabilitation (DVR)
-Yukon-Kuskokwim Health Corporation (YKHC)
-homemakers
-Headstart
-Association of Village Council Presidents (AVCP)
-Division of Family and Youth Services (DFYS)
-school social worker

A service provider agreed to contact the named individuals, select a meeting place, and to coordinate the initial meeting.

2. After further discussion, it was decided that it would be good to have two projects going on at the same time so the two groups could learn from each other. It was decided that a second site, Bethel, would also work toward developing parent support. A parent agreed to ask his wife to begin similar efforts in Bethel. It was agreed by the group that the parent and a service provider would work together in planning a carrying out this project.

3. A parent agreed to continue to talk with the legislature and to do legislative activities that would open up opportunities for parent-to-parent support activities.

Primary Issues

These are key themes that were identified by the participants. These themes were put together by the facilitators and two local service providers following the first day's discussion groups, and then reviewed and revised by the total group the following morning. These themes are written here in the categories used in the 1990 Report by the Governor's Council.

Housing

Need village-based temporary place for people to stay who are in crisis.

Need more village outreach.

First choice for people over 18 is to live with family or not far from home. Begin with this assumption when designing services and allocating dollars.

The second choice is foster home, and the last choice is a group home.

Need a community/village planning committee to solve problems.

Need community/village based support groups. Need 1:1 contact with people listening and asking questions.

There is a need to regenerate cultural interest in maintaining village life.

We need churches/AVCP/local groups more involved in housing issues.

Need flexible housing funding that pays for what is needed for each individual.

The temporary place in Bethel for people to stay when they come to town for services.

We need mental health supports for people in villages so they can stay in their homes.

Need a contact in each village so they know what is available.

Need a collaborative way for schools/families, and communities to continue to support individuals after school is over.

Need respite care during subsistence.

Civil Rights and legislative activities

Need rural and remote village representative at legislature.

No more discrimination with the use of school facilities.

Need equal access to supports regardless of severity of disability.

Need a more organized influence on politics in Juneau -- parents.

Parents need to involved at state and legislative level -- can help teach parents their rights.

Health Care

Schools just aren't ready or able to support kids with multiple handicaps and medical support needs. It leaves the parents without any support and increased emotional strain.

Parents with children with medical needs have little to no support and don't know what resources are available.

Employment

Students need more on the job training at local businesses during school.

Schools and service system can identify volunteers to support people in getting and keeping jobs; schools should do actual job training.

Develop system that continues to support people after they graduate.

"Widen" the standard definition of work that schools and systems use.

Provide a go-between for the school and community employers.

Collaborate to promote more jobs. Can DDMDD schools and others work to help with economic development?

We need meaningful things for people to do during the day. More community projects, workshops and individual jobs.

Definitions need to include subsistence.

More dollars for support services.

Community needs to participate in village council decisions about jobs.

Individual and Family Supports

It is difficult to develop parent support in remote village where there are only a few families.

Involve community and civic groups more.

Community needs to be taking more responsibility for providing support and not leave it all up to the government.

Need more organized ways to get together (families and community members) to get informal supports.

Need to provide sibling support and information.

Need someone to intervene when things go wrong.

Provide supports to individuals with disabilities in the community so that they behave appropriately.

Build leadership in the community, to include disability issues.

Find specific ways for individuals to get involved in activities, match a person with a person; emphasize group activities, live music and potlucks.

Family pride doesn't have to mean that families are isolated.

Helpful things for community members to learn include: how to approach people with disabilities; encourage them to socialize; accept the person; see people's abilities; learn to communicate; and do advocacy

Need to organize more events for families and children to get together to socialize and do activities together, for remote areas also.

Get parents more involved in planning at the state and regional levels. We don't even know what's going on and what is being planned for the next year. The state isn't aware of remote and rural village needs.

Could the state fund a hot-line to get information about what is available and who can help so when parents have a need they can call someone.

Parents do not know what resources are available until it is too late (i.e., medical, equipment, etc.)

Lack of coordinated effort of resources on a regional basis.

Need a go-between parents and school district, need support and advocacy separate from the school district.

School district could support parents in getting support groups going.

More teleconferences in rural areas among family members (SEPTOR did it.)

Education

Begin very early for children with disabilities to be around kids without disabilities, and to make it a school priority for kids to play together. Having friends and feeling accepted creates atmosphere for students to learn.

Help teachers to do group class exercises to get student acceptance of students with disabilities, and students with other apparent differences. This is critical for all students with other apparent differences. This is critical for all students to participate to reduce stereotyping.

Teach and communicate information to the community about people with disabilities. The community does have this responsibility; it is not just the school's job. Activities could include: media blitz; parents tell real stories with a call-in afterwards (radio); story hour at library should have disability stories; reach professionals and all citizens.

Need to identify specific social skills that are necessary for students to make friends and get along, and tech those at school.

State graduation requirements are not appropriate.

Schools need to teach more community values like traditional values, crafts, foods, etc.

Schools need to teach more: socialization skills, healing process, talking circles, self-esteem, making friends.

Need to train administrators and teachers how to listen to parents on a daily basis and at IEP time.

Administrators and teachers need to know more about available resources.

Kids need to be able to play more. Too much structured time in schools, no time to make friends and it is important for children to make friends early on.

Students need more self-help skill training at school.

Administrators and teachers need to know parent rights and to work with them when they exercise those rights (there is resistance at administration level).

Need to identify skills needed in the community that make sense to the parents and then request teachers to include it.

Year around activities are needed through schools.

There is a major lack of trained education staff; need more Alaska Native teachers and administrators and specialist (P.T., etc.); train teacher aides to be teachers; do we need to think about the qualification standards?

Kids with disabilities need to be a part of regular classroom, but with the supports needed.

IEP's should involve the student's whole life including all family; transition from home-based to center-based, etc.

IEP's promise lots, but there are never the resources to back them up.

IEP's should focus on what student can do, and parents to contribute to what kids can do and should be learning.

IEP's should be more positive. We want good things written. Reading negative IEP's makes us sad and depressed. Choice of words is important. The IEP should reflect what the parents said, so they recognize it.

More communication between school and the community.

May be need to change qualifications for aides an teachers.

Trying too hard to graduate kids and give them a diploma. This should not be the major goal.

Income

Need increased SSI/Medicaid and other programs.

Can OBRA help us?

System Recommendations

Need ongoing forum with DVR, HSS, DOL, CRA, DOE, DD, DFYS, Corrections (and people involved most actually have power to make changes) to meet regularly to look at community needs and make systems recommendations. The current interagency Coordinating Council may not have adequate representation to make change. There is a need to develop a birth to death plan of services and supports.

Encourage integration (the State and region) should have policies, etc. that encourage integration and family-centered involvement and activities.

State should make information available to families in rural and remote areas.

All people who work with children should have an understanding of children with disabilities and how to get acceptance from other children; all children are their responsibility, not just children with special needs or children without special support needs.

Need more after school activities for children with disabilities to be included with other children.

Add steps in transition from preschool to kindergarten.

When the State allocates dollars, it is never enough to serve the whole region and the remote areas aren't included.

Facilitators' Impressions

1. The frustration level of parents from the villages was extremely high, with little trust from professionals including medical, school, and community services. Parents felt they had not been listened to, and heavily criticized as trouble makers when they tried to stand up for their rights and desires. They gave several examples of knowing what was best for their son and daughter in specific situations and not being consulted by the professional, and things going very wrong (based on the professionals intervention or lack of). They gave may examples of being frustrated because they felt they were be-

ing perceived as a "burden" by professionals. Due to the lack of trust and lack of family support, a couple of parents were thinking about how to create a segregated facility (classroom) and nursing home so that the particular medical needs of their children could be met. They were past the point of believing that they could get help from professionals, the school or their community. They felt that there could only be "qualified" paraprofessionals in a segregated, special facility designed to meet needs of children with significant medical or other supports.

2. There were several parent stories that related to a lack of information about resources and learning after the need had passed that a resource would have been available had they known about it.

3. The parents know they have many rights and were frustrated that professionals weren't allowing for those rights to be upheld. They wanted teachers to work hard on their behalf in getting what they wanted instead of standing in their way and always talking about how hard it is to get something done.

4. There were parent stories that related to getting support early on when they were initially dealing with accepting the disability or medical conditions. One parent told a story when an elder had helped her admit that her son had some disabilities, but that she had no support for a long time and was in alot of emotional pain denying her son's need for special supports. The elder said to her, "Bring your son to the community, be proud, and people will accept him the way he is" (paraphrased). Up until that point, she was denying the situation and felt very isolated and afraid. There was no contact from other parents and the doctors were not at all helpful to her.

5. We kept noticing that the terminology was a large blockage to getting parents to tell stories. People know what supports they need, but it's difficult to fit the need and stories into terms like "respite" and "shared-foster care". This backs up what we know of the importance of listening to stories and building supports around specific individual needs rather than fitting parent's story into a category of service. It furthers the chasm that exists between service providers and families. We need to use language that builds understanding rather than separates professionals from families.

6. Several of the Native folks at the forum felt that the way the forum was organized was not sensitive to Native culture or issues. They said that the forum issues should have been presented to the Village councils

months before the forum so they could have an opportunity to formulate a policy, and then come to the forum with a position statement. The facilitators' impression is that this statement demonstrated a misunderstanding about the purpose of the forum. The origin of this misunderstanding is not clear to us, however. The advertisements seemed clear, and the initial introduction at the meeting explained the purpose and intent of the gathering. It may be helpful in the future to contact village councils and ask for support in conducting the forums and getting help in developing the structure.

Anchorage

Thursday, November 2, 1989 6:00 - 9:00 p.m.
Friday, November 3, 1989 9:00 - 12:00 Noon

Forum Purpose

The purpose of this forum was to generate ideas about how to create more jobs and job support for individuals with disabilities without receiving more funding.

Meeting Structure and Attendance

There were about 40 participants in attendance, mostly social service personnel including Division of Vocational Rehabilitation (DVR), special education teachers, Alaska Specialized Education and Training (ASETS) program, Hope Cottages, Association of Retarded Citizens of Alaska staff and board members. There were also approximately ten parents attending, and seven persons with disabilities.

The first evening session consisted of information gathering from participants about what was currently happening in Anchorage. Topic areas included: what people with disabilities were currently doing to get jobs; what the service system was doing to help people get jobs; what the community is doing to get people jobs; and what people directly around a person are doing to help get a job. An associational chart was also made which listed all the formal and informal associations that people attending the meeting belonged to as a way of building possibilities for contacts and relationships. The second day consisted of participants developing a strategy for the next step to try to develop more jobs and support without getting new dollars.

Community Action Plan Outcomes

Participants agreed to schedule a meeting, and form a core work group. As a demonstration project, the group will develop strategies to work with 3 individuals involved in the ASETS program. The plan is to create circles of support around them with people who are not paid specifically to provide those supports. The group will look at several issues that were discussed during the second day including:

1. Ways to get employers to arrange or plan for another employee at the business or organization to provide supervision and/or training, rather than relying on the social service agency to do job development, training, and

supervision. This clearly represents a major role change for ASETS program staff and will require a shift in thinking and a change in activities that staff do.

2. The group will look at ways to incorporate participation from community citizens (identified through neighborhoods, organizations, clubs, etc.) who have an interest or activity in common with the individual with disabilities, to participate in the individual's planning process and to make commitments to develop a relationship and provide informal supports or to do activities with the individual.

3. DVR will look at how to provide services to individuals with a commitment from the employer to either provide long-term support or arrange for informal long-term support from families or a core group.

Primary Issues

The participants at the group kept the newsprint so that they could use the information at the next planning meeting. The primary issues that were identified within the topic area were:

1. Parents want someone to be responsible for knowing early on if their son or daughter has a problem at the work setting, and to let the parents help problem-solve before it turns into a crisis.

2. Because DVR is short-term support and must have commitment from an agency to do long-term support, there was discussion about the need to get DVR to re-evaluate this requirement and/or alter it. Participants have asked DVR to tell them how they can formulate a letter that endorses the recognition of informal supports as part of the long-term support commitment. Can families submit a letter of intent to provide on-going support? Could a group of committed individuals make a commitment to provide long-term, on-going support?

3. In order to get and use informal supports, the service agency staff will need to look at changing roles for staff. It may mean assuming a coordinator and/or technical assistance role. It also may mean giving up some control to employers and empowering employers to be responsible for as many activities, such as job development, training and supervision, as they are interested in doing. There is a need for employers to be able to claim success at doing supports without outside agency staff and to experience the benefits (personal relation-

ships and cost-effectiveness) of employing an individual with disabilities.

4. One person indicated that one of the hardest things about getting jobs is getting the employer to buy the service.

5. The consumers who were present gave several examples of the service system not accommodating their interests in terms of receiving employment related supports. There were also examples of consumers who were getting supports that they desired.

Facilitators' Impressions

1. There was an incredible spirit of cooperation among participants, even though there was discussion about very difficult situations, including lack of funding and lack of successful experiences. Many believe that the "system" is not able to meet the needs of people with disabilities. The agency staff, parents and consumers were very respectful of each other as human beings, and worked well in a problem-solving process.

2. Participants at the forum were extremely well connected to their communities, listing about 60 organizations and clubs, etc. that people participated in. It is a shift of thinking to include people from the community and these organizations as creating relationships with people with disabilities, and creating opportunities for informal supports to replace some social services. No one that we are aware of is focusing on creating relationships in the employment setting, and it was very encouraging to hear the enthusiasm from the group for creating these new relationships.

3. A long discussion happened the second day about the shift that service agencies need to make towards getting communities more involved. Several of the service providers said that the role of employment service organizations needed to change dramatically; to shift from the role of providing direct service to the role of supporting employers by providing technical assistance so that employers could perform the functions of training and support. This discussion is part of an underground trend in organizations who are providing the most innovative supports across the country at this time. There are several demonstration projects being applied for at this time that embrace this concept, and have corporate sponsorship attached to the proposals.

4. The idea of working with DVR in helping them to re-think how they define long-term support commitments will be a critical link in any informal support strategy. Agencies will still need funds to assist employers in understanding what employee training will be needed, for offering support to employees in companies in learning about disability issues and helping them to not be afraid of persons with disabilities, and for staff time to work on building relationships and nurturing further opportunities in the community.

5. The core group of people assembled the second day were very strongly attached to promoting values which centered around individual needs rather than service agency options, and were very interesting in thinking about opportunities and possibilities that are innovative and require re-thinking some of our major assumptions about communities, agencies, and persons with disabilities. One of the comments that frequently came up was that they have to be innovative because they are in the trenches actually getting the job done, and don't have the luxury of talking about programs, models, and rules and regulations. I got the distinct impression that they would do whatever it took to create an opportunity for a person they were working with.

Wasilla

Tuesday, November 7, 1989 6:00 - 9:00 p.m.
Wednesday, November 8, 1989 6:00 - 9:00 p.m.

Purpose

The purpose of this forum was to gather information in an open-ended format, and to identify a few activities that participants wanted to get together again to work on.

Meeting Structure and Attendance

This group included about 15 participants including several adults with disabilities, three special education teachers, several service providers, about four parents who were not also professionals, a legislator, and the secretary for the special education director. Information from the discussions was recorded in the seven target areas identified by the Council.

Community Action Plan Outcomes

The group identified three activities that they wanted to work on, and participants volunteered to organize a next meeting.

1. A parent was named to be the primary person responsible to organize a parents group to include consumers and parents, and other interested persons. The parents have recently been working on getting a group together. The focus of the group will be primarily to:

    a. share information with each other and the community,

    b. provide a support system for families who experience emergencies,

    c. welcome new parents (welcoming packet of information and phone numbers),

    d. provide education opportunities for the parents on topics such as SSI and wills and guardianship, and

    e. educate the legislature and community.

The group will also become involved in doing planning and program development with local programs. They will ask the school district for some dollars to pay for the mailing of a newsletter. The first newsletter will be an announcement of the purpose of the group, provide information about the first inservice opportunity which will be on guardianship and wills provided by Advocacy Services of Alaska (A.S.K.). The parent group will schedule meetings on an as-needed basis.

2. A group of three parents agreed to meet with staff at the SSI office to address many of the issues discussed during the meeting. One of the parents will take primary responsibility for initiating this meeting and pulling people together.

3. A consumer will begin a People First chapter. Three other consumers volunteered to help.

Primary Issues

The primary issues identified are listed in the target areas identified by the Council:

Civil Rights

1. Need People First chapter to teach people with disabilities and citizens in the community about the rights of individuals with disabilities.

2. One individual indicated that A.S.K. did not help him when he called for help about SSI; he lost his benefits and got behind on his rent which resulted in losing his home and now having to go to court to work out arrangements to pay the rent that he owed. The individual did not feel like A.S.K. had provided the help that he needed, so he didn't call them back.

3. People felt that A.S.K. had provided much needed support in other cases and that there was more of a need for this kind of help locally.

Employment

1. Need more jobs in the community; one person wanted to work at McDonald's.

2. Several adults mentioned wanting to earn more money to pay for rent and food.

3. There are major transportation problems in Wasilla -- staff drive people to work at supported work sites and the group home staff help provide transportation.

4. Two people desperately want and need jobs so that they don't have to move. One person is afraid (after his last IEP), because it was mentioned that he may have to return to Texas because of the lack of support here. He was feeling scared about that.

5. One person is in his last year of high school, has a part-time job at high school and needs help planning a job after high school.

6. One person wants a job at the hotel/restaurant.

Income

1. One person lost his home because of SSI error and lack of information. There are major problems here with SSI office: inconsistency with information provided; having different telephone operators giving different information about the same questions; and people losing benefits that they are entitled to. There is a toll free number, but people receive inconsistent information and need someone locally to provide clear information.

2. Advocacy Services of Alaska (ASK) can be helpful with advocacy and SSI but need someone locally.

Individual and Facility Support

1. Want to start People First chapter to provide information and support to individuals with disabilities. ARCA may help start, may connect with Anchorage group for support.

2. There is a major lack of respite care -- only four hours available per week per family and there is really not enough funding to provide that much (not every family requests that much). The lack of respite care results in many problems with families, sometimes threatens family stability and their ability to stay together in their home community.

3. Families want other respite options such as periodic weekends or a week at a time.

4. Shared foster care was not available in Wasilla but was of interest to people.

5. Parents in Wasilla and more rural areas need parent-to-parent support. One parent drove 4 hours to this meeting (in ice and snow).

6. Parents need access to information about services and resources. A directory of services is needed, maybe to be available through schools. Parents, consumers, educators, service staff, and everyone needs access to clear updated information. There is a directory available through Borough; need more information sharing between schools and Borough.

7. Need a local parent group; effort has been underway but a group is not yet formed. There are 7-8 families with children near high school transition age, and this is the impetus for the group so far. Families are interested in respite care, residential and work programs. There is major concern about what is going to be available after high school.

8. ARCA and Easter Seal provide some post-high school activities, but there is usually no 1:1 support available, so people with significant disabilities can't attend.

9. Families want a variety of services after high school including programs that are similar to what people get in high school.

10. One parent had a licensed foster care home but it wasn't used because no one was referred and the license expired without notice. This family experiences a lack of information, services, and support, and is considering outside placement of their child.

Education

1. Need more teachers and classes.

2. What support after high school? No services. Wait lists are too long or non-existent for services that parents/consumers want.

3. Administration and state agencies should gather information from community and ask legislature to fund what is wanted, not what the service system thinks is needed (like this meeting). There should be many more opportunities like this meeting and the information gathered needs to be used by state policy makers, and those reports and budget requests to the legislature should include testimony by individuals with disabilities and family members.

4. One recommendation for how the community can educate legislators about what is needed, was to send public opinion messages that are individualized and personal (not form letters) and include phone numbers so the legislator can call and talk about the issue.

5. One family member wanted increased friendship building at the high school. His 13 year old daughter has no peer group and this was very difficult for her. At school, most of the time she had a 1:1 aide, and only participated with other children during P.E.

6. Teachers could facilitate friendships with peers at school by teaching children about differences.

7. Regular education teachers could use information during college training on working with children with developmental disabilities.

Housing

1. Don't know why state doesn't give money to group homes. Need all kinds of options. Board and care home operator is also unable to get much funding from the State, and receives no referrals. She provides support to people she finds in the community who need a home.

2. There is no apparent planning by the State to provide supports after high school; if there is they aren't including parents or consumers from rural areas in the planning.

3. One adult wanted to live in an apartment in Wasilla, but people were considering sending him to Anchorage. What he wanted was: to live alone, someone to talk with about how to get along better with people, how to manage his money, help with health concerns -- someone to go with him when he had to go to the doctor; and help with cooking.

4. Parents do not have a voice in planning alternatives. The state should ask parents and consumers.

5. Individuals with disabilities should be asked what kinds of programs and support they want before programs are developed.

6. Many policy makers, legislators should live with someone with a disability 24 hours a day before making decisions about what people need.

7. One person will have to move soon if he doesn't get support and a job. What he wants is: help with managing his money, wants to live in an apartment in Wasilla with a roommate; help with bills; it's scary living alone; and it's scary thinking about moving away.

8. One person wanted to live in an apartment and have his Mom and friends visit. He wants help with finding a job and his budget. He described ways that his life would

change if he had his own place -- he would feel good inside, be out of school and have new friends, and get a goat and a dog.

Facilitators' Impressions

1. Several people commented during the breaks that this was the first time that consumers and parents were really listened to, and that it was important to hear what services people really wanted from the system, and to hear how things weren't working. This included parents, a legislator, and social service staff. There is clearly a need for consumers and parents to participate in local, regional, and state planning processes to help define what services are needed before the services are developed.

2. Several adults receiving services either had or were in the process of having to move out of Wasilla due to lack of services after high school, and lack of support in apartments. Parents expressed how the lack of respite care and other services had threatened their families staying together (either currently or in the past). When asked, "what would it take?" the support needs seemed to be things that should be possible in a rural areas ,such as: more friendship building at schools, respite care, shared foster care, and various levels of individual supports for adults to live in their own apartments and houses. A few adults were looking at having to leave their community, and the supports that they described as needing to stay in their community, included things like: cooking, someone to talk to when they need help, helping manage money paying bills, job, etc. There are almost no services available for people in Wasilla. It would seem to be beneficial to do more problem-solving with this community about how to get more services that people want and how to think about informal supports for one issue or need at a time such as transportation.

3. The consumers that provided information about needs on the first day weren't present on the second day to do action planning. The group's plan of action on the second day did not reflect all of the services that the consumers had requested to stay in their community, particularly getting supports to live in their own apartments. The consumers did an excellent job of stating what supports they wanted, which were individualized supports in their apartments in their home community. Perhaps it would be helpful for parents and people with disabilities to have opportunities to listen to each other and to build service recommendations for all of their interests.

Soldotna

Thursday, November 9, 1989 6:00 - 9:30 p.m.
Friday, November 10, 1989 9:00 - 12:00 Noon

Purpose

The purpose of this forum was to receive comments from the community members about unmet needs, and to develop an action plan to address priority issues identified by the community members testimony on the first day.

Meeting Structure and Attendance

There were approximately 18 parents present, three students with disabilities, six teachers, and seven service providers; it appeared that several people did not sign in. The structure of the meeting was formal, including formal seating arrangement with a panel in front, use of a microphone, and the local coordinator requesting "testimony". Many people indicated discomfort with the microphone, but people did talk and the testimony went on until 9:30. The meeting was tape recorded, and the panel recorded testimony by each person's name.

Community Action Outcomes

Eight focus areas were selected for people to do follow-up activities in the next two to three months. Interested participants signed up for areas to work on and one person was selected as the coordinator for each area. (The coordinator's responsibility was to schedule the meeting, and not necessarily to facilitate the meeting; the facilitator for each meeting will be determined by each group.) The coordinator's responsibility was to schedule a meeting, add other people to the group from the community who were not connected to disability issues, and then to share information from the meetings with this community forum's planning group which will continue to meet. The eight areas are:

1. The group wanted to develop a resource center that will:

    a. distribute information and provide education: programs, technical information, working together,

    b. be a focus point to build relationship between parents (welcoming new parents, linking parents with children with same or similar disabilities, doing outreach),

c. be an equipment sharing/information/bank,

d. employ a resource coordinator,

e. be a voice in political advocacy,

f. promote self-help/volunteerism,

g. network with other centers (what opportunities are out there?),

h. publish a newsletter,

i. increase public awareness.

The resource center will contain and distribute information regarding services; provide linkages between programs and people; provide information about specific disabilities; provide a focal point to build relationships between parents; have information about equipment sharing and exchange opportunities; have a resource coordinator paid to keep it together; do political advocacy; self-help and volunteerism; do networking with other centers; contact new parents and help connect parents to other parents; do a newsletter; begin support groups that are needed such as fathers or siblings support groups; and educate the public about people with disabilities. This was the priority need that was identified. Participants felt that many of the other needs could then be addressed when this is in place.

The questions that still need to be answered by the group include:

a. Who is going to govern the Resource Center and who will do the planning?

b. Who will run day-to-day operation?

c. Where will it be housed?

d. What will the budget be and where will the dollars come from?

e. What is the mission statement, and goals and objectives?

Some groundwork has already been laid for the center to be housed at the school, to receive seed money from SEPT, and Mary from the school district will request dollars next year from the school district if that is a priority for the community.

2. Housing and supports. Volunteers from Homer and Seward will work together on this task.

3. Legislative action, including entitlement services; minimum quality of life; funding equality for all children with different disabilities; and guaranteed services. Several issues were included here: need for reasonable caseloads; developing a voucher system for families where the families decide what to spend the money on: having equal care opportunities regardless of funding source or disability; addressing the inequities of foster care and home care; broaden the definition of who is eligible to include elderly, deaf, blind; guarantee basic level of funding; Medicaid waiver; and addressing the waiting list.

4. Better access and representation for state and federal funds, such as representation from Peninsula on Governor's Council.

5. Two parents will look at the availability of transportation for people who experience disabilities on the Kenai Peninsula.

6. Another group will look for ways to develop recreational opportunities that are integrated.

7. A group of four people will gather information on extended out of home and school activities, including child/day care, summer activities, summer school, and drop-off respite for people of all ages.

8. A group will investigate child/day-care and respite care opportunities that are integrated and extended respite opportunities.

The planning group will reconvene within two months. The coordinator will set up and notify people by the second week in January. The issues groups will meet to: 1) describe the problem, 2) suggest strategies, and 3) to identify linkages and resources. Each focus group coordinator will invite at least two people from the community who are not connected to disability issues. The coordinator of each meeting will assure that the information from the group is brought back to the planning group. Each group will select one key component to start with.

Primary Issues

The parents and students did an extraordinary job of telling personal stories that illustrated their needs from the service system and community. The recommendations for community

action on day two did reflect the participants' testimony on day one. The issues are summarized here by the topic areas identified by the Soldotna planning committee; housing; community collaboration; standardization of quality; legislative advocacy; state, local and federal funding, and increased public awareness. The facilitators added individual and family support.

Housing

There needs to be housing supports extended beyond Soldotna/Kenai to include Homer, Seward, and Cooper's Landing.

Homer - There were several Homer residents present at the meeting, and several letters from people unable to attend that were read. Three adults with disabilities from Homer commented that they needed residential supports, and supported employment in Homer. There are currently two options for young adults at Homer:

1. to move out of their parents home and take their chances patching a network of community support, or

2. live with parents forever.

Their proposal for independent living support was not funded by the Division of Mental Health and Developmental Disabilities (DMHDD). They are receiving some independent living dollars from the Division of Vocational Rehabilitation (DVR) and are housed at the Mental Health Center. In July 1990, these dollars will only be available on a fee for services basis. DMHDD will need to contribute funding in order for limited services to continue. They anticipate employment for 3-10 people. They want localized supported employment services in Homer (limited services currently available from the Frontier Program in Soldotna). There is no long term mechanism through DVR to obtain DVR dollars. Homer residents also reported a need for crisis respite care, transportation, and case management dollars to provide advocacy to individuals.

Foster Care - Several people provided testimony about the inadequacies of foster care. There are no respite opportunities, no training, limited funding and monitoring. There are also disincentives for families to keep their children at home, because there are more medical benefits available to children in foster care than in their own family home. Foster parents wanted after school activities; opportunities for children to interact with children without disabilities. They reported

the DFYS caseworker to have too large a caseload to provide any support or help.

Standardization of Quality

Need quality structured child care alternatives for families that are adequately funded.

Need to have local programs in the summer for recreation and living skills.

Need to see adequate pay, training, and monitoring of respite care providers.

Group homes should be teaching independent living skills. Who is monitoring?

Foster care homes should be monitored and held accountable for services.

Need increased money for foster care and other programs if you want quality services.

Child care providers should make adequate provisions for special needs children.

Should monitor direct care workers in all programs. Are dollars being spent on people with disabilities appropriately?

There should be a minimum level of quality of life for all people who need services; government should set policies and guidelines based on some level of quality of life.

Legislative Advocacy

Need special transportation and access in rural communities.

Need entitlement services after high school and guaranteed dollars.

Advocate for more in-home services of what a family needs and wants. A personal case manager for a family with dollars, and let family make choices about what supports are provided. Parents manage child's affairs and hire who they want; would cost less than through the bureaucracy. Parents need more voice in services.

Parents get a voucher - group consensus - and hire who they want.

Need to look at SSI regulations and how the system punishes families, disincentives for family staying together, earnings, etc.

Advocate for civil rights for citizens with disabilities.

Advocate for children to stay at home and acknowledge importance of families.

Fund families in their needs, not agencies. Agencies need to be accountable to families.

Parents to participate in ongoing information to legislature about what needs are.

Families need child's benefits at home, should not be increased benefits for foster care; incentive to keep families together.

Advocate for people who fall through the cracks.

Families suffering the traumas of dealing with high medical costs.

Need local representation on Governor's Council.

Community Collaboration

Providers want to be able to license their home as foster care without going through the bureaucracy

Need summer opportunities for children -- school district funding for summer recreational opportunities.

Want kids with disabilities to get involved in integrated community activities like the Boys and Girls Clubs, need to get the community involved to help provide support to families such as transportation.

Children with disabilities need to participate with non-handicapped peers in integrated opportunities like swimming club.

Need recreation opportunities for kids with disabilities who don't fit DMHDD criteria.

The hospitals and schools should have information about referrals to parent support groups for new parents.

In Homer, sometimes a "patchwork" of support can be organized around a person, but its not always effective.

Need inter-agency communications between Frontier Training Center, physicians, infant learning program, so families can get all information they need (education, medical, counseling, etc.) Lack of information can lead to child being placed out of home. Agencies have concerns about confidentiality.

Need single place to go for information with a staff person responsible.

City and local communities need to take responsibility for recreational opportunities that are integrated. Could train volunteers. The city could provide $'s for adaptive equipment, transportation, and participation costs.

Individual and Family Support

There is need for sibling counseling and family counseling - support groups.

Parents can help parents -- need a parent support group, need a coordinator. Parents can most frequently provide the best support and the most technical information.

Kids with disabilities need to participate in regular day care, not segregated.

A resource center is needed for Kenai, Homer, Seward - need support dollars.

Need equipment exchange program as you outgrow some equipment.

There is a need for a centralized equipment loan program for special adaptive equipment.

New parents need information, support in communicating with doctors, understanding finances and services, legal rights, school, etc.

Need parent support group and other advocates when parents get burned out.

Son needs training at home now (in high school) to prepare him to move (cooking, cleaning, etc.); he is not getting training in independent living at school.

Bring a local person home from Harborview Developmental Center. He needs a supervised apartment living program. He left his home community due to lack of supports available in programs that he was participating in.

Ten people in the community needed increased support.

Seward - residential options needed for at least three families - need one person locally in Seward to advocate for residential supports.

Foster care inequities: receive $400-600 from the Division of Family and Youth Services (DFYS), and $1200 from DMHDD.

After high school, no guarantees for services, place emphasis on home services centered around person; have person contract for services.

Best thing for a child is to stay in the home and we need to restructure the program to keep the family a unit.

Single parent needs integrated child care licensed and capable to address support needs of the child.

When both parents work need summer recreational activities and after school activities.

Need transportation to and from existing programs.

Families with an individual with blindness need training in Braille.

At least three people in Homer need funding for employment training; the same three people need residential supports.

Because there is no longer term support in Homer, there is no DVR funding.

Need to work with families and address their needs, not agencies.

When families need to travel for services, they need financial support for travel and hotels.

The lack of services and special education classes prevented a child from staying at home.

Parents need to have knowledge of all resources. Physicians, social workers, etc. also need to be knowledgeable so they can inform families.

Adults need support with dressing, etc. to integrate better in community activities.

Many young adults in Homer feel that there is nothing here for the future and they may have to move.

Need to listen to parents. Need to be able to contract services on a case by case basis for each family.

Families want to stay together. State needs to recognize importance of families and give dollars to families, and let the family spend money on practical things that are helpful for the family.

The system seems to punish the family who makes a good living.

State, federal and local funding

Need to advocate for services for Homer - residential and employment, and case management coordination (advocate).

Need to educate the state that families are important and give support to families by giving them money for what the family needs (insurance, medical, respite)

State should give dollars to families and individual with disabilities, not service providers.

DFYS needs more staff for licensing foster care and recruiting foster care providers.

Need funding for more respite options, drop-in, integrated options.

Increase rates for foster care; there are current inequities.

There is a need for funded summer school and programs after school; children lose some skills during the summer.

Need state and federal dollars for recreation programs - need transportation.

Need funding for supervised living for adults or children will have to leave the community. There are 10-12 kids who will graduate from high school in the next five years.

Need flexible integrated housing and residential supports, instruction in independent living skills.

Need increased funding for salaries, training, and screening for direct care staff.

Need to listen to families regularly in planning and funding services.

Need help organizing a parent group (and funding).

Increased Public Awareness

There is a lack of information available to parents and the community about people with disabilities, and resources and supports available.

Agencies need to provide better information to the community about their services.

There needs to be a high profile organization that parents know about, particularly for new parents when they are ready for support.

There needs to be information and referral for people who have disabilities or needs for services, but who do not qualify for services.

Facilitators' Impressions

The outcomes of the forum were positive, to develop a resource center and the other activities mentioned above. However, it appeared that due to a lack of other resources, the parent resource center may be initially governed by the school (particularly if the center is funded with school district dollars next year). There has already been several meetings among some parents and the school district to begin the parent resource center, to be located at the school and funded by SEPT, and perhaps with school district money next year. There was some concern by some parents there about their interest in the parents controlling and governing the parent resource center, and that it eventually should stand alone, away from the school district. It appeared that the people present at the meeting went to the school district for support because they didn't feel there was other support in the community or alternative funding to begin the resource center.

Fairbanks

Monday, November 13, 1989 8:00 a.m.-5:00 p.m.

Purpose

The purpose of this forum was to gather information from participants about what supports were needed, and to identify current issues in the service delivery system.

Meeting Structure and Attendance

There were approximately 35 participants including people from the Infant Learning program, Fairbanks Resource Agency, the Governor's Council for the Handicapped and Gifted, North Star Rehabilitation, Fairbanks North Star Borough School District, Hutchison Career Center, the Division of Vocational Rehabilitation, the Exceptional Family Program (military), and about 12 parents, and three people with disabilities. People were invited to attend for specific blocks of time: service providers in the morning session; people with disabilities during the noon session, and people involved with the school district during the afternoon session. There was some cross-over with parents attending the noon time and afternoon sessions.

Since the purpose of this forum was only to document issues, the topics discussed are listed here in the categories provided by the Council.

Primary Issues

Individual and Family Supports

A grandmother left a written note because she didn't have time to attend. She was stating the need for in-home professional care for her granddaughter, 2 hours a day, in the morning to get her bathed and dressed and ready for school. The mother works part-time, is a single parent, and has requested Medicaid funding and hasn't received any support. The grandmother picks up her granddaughter after school every day. She was also stating the need for teenage support group for children with physical disabilities.

Need interpreter services and communication supports for children who are deaf, and training for teachers and students in communication. Also need independent living skills training at home for students with deafness.

Parent support group is needed. Parents need to be able to provide information about resources to other families including finances, medical issues, taxes, etc. Parents need other parents to talk with, especially at villages where there are no other parents. Parents know lots of things that professionals don't know...little facts about where to get things, resources...How can they share this information? If you don't know something, it's hard to get what you want. You get tired of the battles. There is a need for information for parents about local resources and services, and resources in nearby communities. The Governor's Council is in the process of updating a resource directory.

Air force base is desperate for contacts. Families in the military need to know what services are available in the community.

There is a lack of services for adults with dyslexia.

There is a need for after school recreation activities for children. There is a task force advocating for an integrated play facility.

Need entitlement services after high school. Parents expressed concern that their son or daughter would be on a waiting list forever. Parents need to plan and look forward to supports after high school and for when family members aren't alive anymore.

Families and children need transportation options. Families become isolated from the community because of the lack of transportation to community activities. For example, there is a culture activity at night that few people can get to. There is a "stroke" parents support group that offers no transportation except Van Tran (not enough room for everyone).

Need family and other support for families with babies at risk for Sudden Infant Death Syndrome; mother told the story about her daughter, and the incredible amount of stress in having a baby at risk for SIDS, and how some supports would have made her first year a lot less stressful. She suggested several supports: family support for families; respite care; someone trained to use respiratory monitoring machine; day care with training staff; training for people on infant CPR; and parents getting connected to other parents to give them information and to try to reduce their stress level. She advocated that SIDS be included in funding for developmental disability services.

There is a need for respite care. This is very important to the family, to help keep it going. DON'T CUT RESPITE

DOLLARS! It is a safety net for the family. Several families agreed. There needs to be crisis respite care. Families cannot always plan ahead. Parents may have up to 40 hours/month and 7 over-nights a year; based on income. It is working well for families when it is planned, but not so well when it isn't planned. There is a shortage of respite care providers. Some of the reasons for the shortage included: it is a hard job; provider usually provides own transportation; the pay is $7.50/hour and no benefits; many employees are students who become trained and then leave. There is a 3 month waiting list for respite. The availability of respite care fluctuates with funding.

Integrated child care options are rarely available; people turn down families with kids with disabilities because of need for individual care and the high number of other kids to take care of (up to 12 children).

One parent indicated that all of her income goes to babysitting costs. She pays $400/month in taxes for hiring a home babysitter; she pays $735/month to the babysitter. Literally all of her earnings go to the babysitter costs, but she works to get respite and because she wants to. She wanted an integrated child care option that she could afford.

There is a child care assistance bill in Alaska where the state pays twice for kids with handicaps, but child care center has to reduce ratio so they end up losing money, and the bill doesn't really provide an incentive.

One parent present was able to get her child into an integrated day care, but it took a lot of work and the child care operator had worked with a child with a disability previously. Need in-home and out of home day care options.

One family considered the current services to be a "life-line" of services now....if anything stops, major problems would occur; she said "please don't cut anything".

Income

Due to income level (even if minimum), parents often don't qualify for services and the family's quality of life is affected. Special medical equipment costs, etc. end up taking away money that would otherwise be available to other family members, and frequently the children need to do with less.

SSI is a disincentive to people staying at work; it is not helpful to family growth.

Education

A teacher who couldn't stay left a note. She asked "What type of physical and occupational therapy should the school district be providing?" She wanted clarification about "only if needed for academic learning", and wanted to know the accurate interpretation of the law.

Infant learning - need speech therapists (went 2-1/2 years without services). There is a shortage of physical, occupational and speech therapists.

Salaries are lower in Infant Learning Programs than school districts (higher salaries and benefits at school). There is a high burn out with Infant Learning; should be able to work a 10-month year.

Not all children are receiving the individual supports that they need in the local Infant Learning Program due to the staff shortage.

Can't increase outreach activities until they catch up with families on the waiting list. Could easily do outreach through hospitals, but there is no point.

P.L. 99-457 mandating services from birth to school age, but there is no dollars.

There needs to be more time to check in on families in infant learning program.

Last year, there were over 100 newborns in neo-natal care unit at Fairbanks Memorial Hospital.

There was discussion about looking at doing IEP process different to meet family needs. Ideas included perhaps doing pre- and post-meetings with the family to determine if their interests had been addressed and if they had any concerns.

There is a Family Assessment Program at the Air Force including assessment and evaluation and individual and family counseling about different issues such as anger, etc. There was a representative from the Air Force who wanted to learn about community resources for individuals with disabilities. Families in the military experience problems due to their moving around a lot , not being eligible for services due to residency requirements, etc. and the added stress of moving a family.

Not all children experiencing delays qualify for school district. Headstart takes some of these children but they are restricted by regulations requiring the child to be three by August 15 and the requirement of only taking 12 three-year-olds.

The school should know more about Attention Deficit Disorder (ADD) and behavior management. Children with only ADD don't get services from school district, but have same needs. There is wide-spread use of Ritilan and many children are diagnosed in the Fairbanks areas with ADD. There is a parent support group of children with ADD. Families have experienced many problems at school because of the children's inability to stay in the classroom unless ADD is under control, which means medication. Teachers need to understand more about the disorder, medication and how to support the child. (119 children on Ritilan in district?)

Teachers need more opportunities to provide 1:1 support when needed (only get aide if more than 31 students; there is no incentive for teachers to want children with disabilities in their classroom.

The availability of post-secondary education and Division of Vocational Rehabilitation (DVR) funding varies depending on the counselor; dollars are available but may need an advocate.

Parents need more information about child's progress or lack of progress early on and not one or more years later.

Schools need someone to act as a liaison between parents and teachers.

Teachers aren't trained to be counselors for families which is sometimes needed. (A teacher pointed out that there is not time for the teacher to teach the student all day, and then to do family counseling at night or after work when the family is busy cooking dinner.)

Schools need to involve families in planning more, particularly at age 16 and older. Families are not involved enough in IEP's.

Need to work individually with families to encourage parents to ask for what they want and to question professionals and professional judgment.

Transition at age 3 -- get teachers to understand parents power and rights. Need to involve parents in assessment and training; parents are professionals

(experts); parent-to-parent support would also be helpful.

Professionals at IEP need to give power to parents, let go of power, listen to parents, and provide support to families.

There is a need for more infant learning services; 4 families are waiting for assessment; 18 families are in the referral process; 17 parents are on waiting lists. The caseload for infant learning is 1:12. There is more of a need for speech therapists.

Need more vocational training and individualized supports for the kind of work that people choose; not just what is available during middle and high school.

There needs to be inter-agency coordination for a child, linkages with all agencies like a "case management" function.

Someone to advocate for the child's rights (not same as family advocacy); to help get the resource that they need.

School was not prepared for daughter's support needs. It took 2-1/2 years to get supports; school was unable to address her needs because of behavior problems; sent her to special school (Barnette School, segregated with 8-10 other kids) and transportation was a major problem.

Many schools have no extra classrooms for special classes.

Military and school district meetings working on school/building needs.

Families in military who relocate often have to start over with looking for and qualifying for support (Exceptional Family Program in the Air Force).

State needs to pay for buildings if students' needs aren't being met; shouldn't be using portables.

Re-allocation of boundaries -- kids with special needs are moved from school to school, instead of planning around boundary decisions.

Lack of classroom space makes it more difficult to integrate children.

What provisions are there for child with learning disability after grade school? There should be math, language, etc. from teacher several times a week.

Self-esteem is a concern for a father who wants his daughter to stay in class with other kids without disabilities and integration is important to him for his daughter to maintain self-esteem.

There is a special education advisory group with parents starting again this week (it has started and failed several times).

DON'T CUT SPECIAL EDUCATION FUNDS; EARLY INTERVENTION WORKS

There needs to be funds for transition from infant learning to summer school activities (especially for 3-year olds).

In rural classrooms, aides aren't always the solution. They are looking at a mentoring program, older kids working with younger children, etc.

The State should ask the school district what they are doing to meet needs of kids who aren't eligible for services. (There is a Youth at Risk Initiative.)

Housing/Transportation

FRA is the only agency in town; there are no choices for adults on where to live in Fairbanks.

There are 12 people on waiting list at FRA for intensive cluster apartment or group home, and no one on the waiting list for independent living.

Need after school activities or programs, need space, and dollars for staff.

Major transportation problems. Parks and Recreation has events, but limited transportation (Van Tran only has six seats). Could taxi services subsidize rates for people with disabilities?

A person who is 27 years old has been on the waiting list for 2 years; wants an apartment with 1 or 2 other people; needs help with clothes, reminders, and someone to check in everyday; maybe about a half hour a day at first, and less as time goes on.

There were several examples where parents requested extra help with reading for their son or daughter and and the school district not providing the support, and denying the problem until the child became behind several

years in reading skills, and then they had to privately hire a consultant for several thousand dollars.

One parent had been waiting for a speech therapist for a few months and had just moved to the area; the waiting time was going to be at least another 2-4 months, and the infant learning specialist said that was being optimistic. Even with funding, there is a shortage of speech therapists (national shortage).

There is a need for community awareness; tax opportunities, speakers, talking about issues, not the programs, talk with the Chamber of Commerce.

Need to transition from school to work...no lag time.

Criteria for graduation - don't deny diploma to get two years extra time.

Can dollars follow student (taking college classes, etc.) Why is it locked into secondary education?

Employment

One person wanted to raise money to go to Juneau to talk with the legislature about jobs for people with disabilities. He is a member of People First.

AIPHA - 20 adults in supported employment.

Want more dollars for adults to choose and learn new job. DD and DVR doesn't fund "next" jobs. Why should we expect people with disabilities to stay in the same job?

Wage waiver - locally determined (DVR?). May need an advocate to pursue post-employment services.

Transition planning - students and families to plan before last year in High School, especially if graduating at age 18.

Families need to learn about services (DVR, DMHDD) and plan earlier.

Job placement strategies are shifting to building relationships and less on tax incentives, etc. Four people on waiting list for supported work at FRA.

Health

Dental care is not available. Salvation Army and Love, Inc. take referrals and there are some dentists that provide some support. However, these are more for emergencies and don't include preventive and long-term care. A parent in the room indicated her husband was a dentist and that he provides service to people with disabilities, and that people could receive dental care by calling Salvation Army or Love, Inc.

There needs to be more readily available training on doing CPR on babies.

People make too much money to qualify for support services, but not enough to buy services on their own. (Medicaid dollars)

Civil Rights

One person wanted to raise money to go to Juneau to talk with the legislature about jobs for people with disabilities. He is a member of People First.

Infant learning should be an entitlement service. Need for entitlement services after high school. There should be equity of services for all kids and families in rural areas.

Need to widen definitions for eligibility (change state to be similar to federal definition).

Facilitators' Impressions

1. The format for this forum was different in that people were invited at separate times, in order to accommodate schedules. However, this prevented a more interactive forum where professionals could listen to parents and people with disabilities to tell stories about what was working and what they wanted more of, which we have perceived as one of the primary values of these forums.

2. There were many innovative and positive ideas presented by Infant Learning Program staff, and that program is very valued in this community. Staff seemed to be very interested in giving the power to the parents and families and were interested in providing family-centered services. This notion was not so evident with special education services (elementary), and it appears that forming a parent support group or advisory council to the school would help to empower parents to receive the supports that they are interested in. It appeared that

people were interested in working together to obtain solutions, but there currently isn't a format for doing that.

Kotzebue

Tuesday, November 14, 1989 1:00 - 5:00 p.m.
Wednesday, November 15, 1989 9:30 - 11:30 a.m.

Forum Purpose

The purpose of this meeting was to gather information from participants about what supports they would like to see for individuals with developmental disabilities in Kotzebue and nearby villages. There were mostly village parents in attendance (about 15 parents), and representatives from Developmental Disabilities, the school district, and senior services. This report is organized somewhat differently than the others; we have simply listed stories that people told, and other general issues that were discussed.

Stories

1. A tribal doctor was invited to come in to talk about how she learned to be a tribal doctor, and to ask her how she thought the practice of tribal doctors could be carried forward when she and other tribal doctors were gone. Parents had told many stories about how they valued tribal doctors (2 or 3 in the villages), and in contrast how the interns (student doctors) that were sent to the villages were not useful. The tribal doctor came in and told her story. When she left the room, three of the parents followed her out of the room for treatment.

   She said that a tribal doctor came to her one year and asked her if she would like to learn from him to become a doctor and use her hands to help people. She said nothing. He came to her a year later and asked again. She said no. He came to her a third time a year later, and she said yes, she was ready to learn. She said he told her now to help people with her hands, and he taught her how to help by talking with people. The Maniilaq Association has recognized the importance of tribal doctors and is looking for two apprentices to work with the tribal doctor and her teacher, who will carry on the tradition when they are gone. She said that people are chosen to be tribal doctors, but they also have to know when they are ready to begin to learn, and then to practice without supervision of tribal doctor. She trained with him for 4-1/2 years, is still training with him and has worked for a year and a half on her own. Another woman in the group wanted to learn these skills to work with her hands, but she said she couldn't because she had "blind hands" and wasn't able to learn.

2. Three women told stories of how the village doctors helped them to turn their babies through massage before going into labor to give birth. Only the Native doctors can do this, and it is very comforting for the women as they go into labor. One woman described that her baby was in the wrong position and the regular doctor didn't know how to help her before the delivery, so the Native doctor turned the baby with her hands.

3. There was no apparent antagonism among people using health aides, the tribal doctors, and regular physicians. People used all three services.

4. At the end of the meeting, the facilitator asked about the lightheartedness of the group and how was it that they were so calm, friendly, and helpful, and full of humor when there were serious needs and issues. They acknowledged that it was true, and at least three people said that their attitude was the result of teachings from elders. The elders taught them that it was important to laugh (and everyone laughed), and that it was important to always help each other (they went on in great detail to explain different ways that families helped other families that needed help getting food, firewood, and gathering around each other when someone died and when someone needed support). The elders also taught them to be self-sufficient (one woman said, "we've been asking the government for help for years and nothing ever happens so we just keep doing it on our own"). A father said all the snow machines and supplies for emergency searches for people lost comes from community bingo. There was one example where a woman needed firewood and the men were too busy, so they all chipped in a few dollars and hired someone from town who needed work to get her firewood. He also indicated that if a parent needed air fare to Anchorage or money for medical purposes or emergency, that people would contribute money. The elders don't believe in going outside for help. They also believed in community prayer. There was a concern that dollars for some activities may replace natural, family and community supports that are strong beliefs of elders and village communities.

5. There was some discussion at the end about the impact of paying people for providing supports that community members used to do out of love, caring, and cultural beliefs. It is difficult for people to turn away respite care money to pay people in their villages, but there was also concern that this could take away from the cultural belief that it is important for people to stick together and help each other when there is a need. There is so little money in the villages that people may want the respite care money, even though the long term effects break down the strength of community. The other

issue that was raised was, what if the money was no longer available and then people were unwilling to provide support without being paid? Service providers have examples of this happening both in Kotzebue and in other areas of the state.

6. One mother had made a trip to Valdez to look at the institution as a possible placement for her son. She was so upset at what she saw, she said she felt so sorry for the children. She said "Where are all the mothers?" She couldn't believe how bad it looked, and she found out that a different person helped someone get dressed, a different person helped with eating, and a different person helped with other things. She felt terrible and wanted to bring all the babies home.

7. Everyone said that what they need is support in the family home in the local villages, not outside the village. If a support has to be outside the village, the closer to home the better, and then transportation costs need to be covered or assistance would be helpful.

8. People liked infant learning supports provided at family homes. Parents learned a lot and felt like the teachers listened well to them and taught them things that were helpful. They received monthly visits, and help working with their kids.

9. Transportation costs is an issue for families, if they have to go anywhere outside the village. There is a need for transportation funding and per diem if people have to spend the night. It would be helpful for financial support to be provided on a sliding scale (would be better than nothing). Specialists don't visit clinics outside of Kotzebue. It would be much more helpful if they went to villages. Transportation costs for medical appointments are only covered for the first visit, if approved by the doctor. It would be helpful to have a place to stay in Kotzebue for overnight appointments.

10. People in villages would like to participate in policy meetings with government, and would like a representative at the Governor's Council for the Handicapped. They welcome people from the Governor's Council to visit the villages to get a look at what the village needs are.

11. There was a need for foster care or shared foster care for 2-3 children a year in Manillaq.

12. Respite care is just beginning in Kotzebue. There is some need for respite care, but it is limited compared to the need for infant learning services. Additionally, there are concerns about the effects on the cultural beliefs and practices where village people believe that

the community provides support to families that is needed.

13. Housing is hard to get for everyone, and jobs are few. Families talked about keeping their children at home together, and were mostly concerned about where their son or daughter would live after they died.

14. One father wanted a placement for his son for a month or maybe up to a year, and then for him to come home again. He takes him out hooking everyday and doesn't have any support or anyone else to do things with him. His son can't travel alone because the gas fumes make him ill. He likes to do mechanical work, fish, and gets wood at home. They use a C.B. to communicate and get help from people in the village if he gets sick or needs help. The local developmental disabilities office will try to find a "big brother" to do activities with him.

15. There is no special education for children age 4-5 years. The special education teachers are not trained to do parent training like the services that are provided through the Infant Learning program. The parents feel a real let-down when their child is four years old. The school district is looking at ways to train the special education teachers how to work with parents and 4-5 years old children. They are hoping there will be some funding through P.L. 99-457, and recently the University has a grant to train special education teachers in infant learning.

    There was a major problem with a special education teacher a year ago, but currently the people from the villages were happy with the special education teacher. The problems before included the teacher not listening to the parents and not responding to parents' needs. Parents would like some say in hiring special education teachers and prefer to hire an Eskimo. IEP's are written annually with quarterly progress reports shared with families. Kids don't get enough special education, only about one hour a day, ands sometimes not enough individual support for each child.

    Parents indicated that it would be helpful to have summer school. They particularly wanted exercise equipment at the clinic for kids to use year around.

16. It is hard for everyone to get work, especially in villages. The Division of Vocational Rehabilitation is just beginning to do something. There is no supported employment. There is no job training at high school.

17. The group felt that there are small pockets of services, and that they need more of everything. There is a need

for coordination of services. Families do not currently have information about what resources are available and what they are eligible for. They would like written information about available resources.

18. Participants indicated that their community villages were more than ready and willing to bring anyone back to their community who had been placed at Harborview Developmental Center in Valdez or other programs out of their home community, if dollars came home with the person. They wanted it clear that services should be provided locally, and money that was available only in other communities was not helpful at all. There are about 10 adults placed out of Kotzebue and nearby villages to Seward, Valdez, and half-way houses. Some people have significant medical needs and need supports that currently aren't available in their home communities. Some families have also moved away. There was clearly interest from the group to find out more about these people and to bring them home if there was funding available.

19. People favored broadening the definition of developmental disabilities so there could be equitable funding for people with disabilities that needed support.

20. People needed funding for medical care. Families were not eligible for Medicaid even with low incomes. Foster care parents (two in the room) did not receive Medicaid funding for their foster child. The interns do not listen to families. Infant learning teachers seemed to know more about medical issues than the student interns, who tended not to believe the parents when they passed on information learned from the infant learning specialist.

21. One parent said that the government really needs to think about doing things differently, and to come see what services look like from the perspective of family members in villages, and to look at where the money was going.

22. Parents also wanted opportunities for training that teachers may receive, in addition to in-home infant learning activities (and parent training). Then, these parents could be a resource to other parents in the village.

23. There is pre-natal care in Kotzebue through the health aides in villages. The hospital pays for first pre-natal visit to Kotzebue and then emergencies only. Mothers who are at high risk go to Anchorage for delivery; other mothers come to Kotzebue or stay in villages with midwives. It costs $100 round trip plus expenses for families to travel from Buckland to Kotzebue. Not every family can afford this. There is some problem with fetal

alcohol syndrome; health aides advise parents of problems alcohol can cause, but don't feel they can do anything else but provide information. There is a WIC (Women, Infants and Children) program available for all parents that teaches about prevention, nutrition, etc.

24. A physician is assigned to each village and may only visit the village every six months. They have seven doctors on two-year contracts; there were previously many problems having several different doctors doing pregnancy checkups. There are 2-3 tribal doctors at the senior center who go out to the villages. There was one parent who was not pleased with a tribal doctor, and several good reports about the tribal doctors. Tribal doctors are frequently unpaid for their work; they just do what is needed when it is needed.

25. The group wanted to continue meetings like this forum. They will ask the Governor's Council for continued funding to pay parents expenses from villages. They found it helpful to talk and listen to each other.

26. There were several great reports about the work of health aides, and the frequent use of CB's to communicate health needs at a family home. Health aides frequently responded quickly to requests for medical care.

27. There is a summer camp that teaches children survival and emergency care procedures. One parent told a story where her son had fallen through the ice a few weeks before and had died, and that children (ages 11-14) revived him by giving him CPR and warmed him up until more help came. They had learned CPR skills at the camp, run by Manillaq. He is fine now. We saw an article in the local newspaper where the children who saved his life were to be acknowledged at a community pot-luck. People indicated that when help was needed, local communities were quick to respond.

Facilitators' Impressions

We learned a lot from family members and people with disabilities at each forum, but we learned the most from the people at Kotzebue (most of the people from nearby villages). The stories that people told reflected a true sense of community, and a strong sense of community values and ties to traditional Native American culture. We learned what community means, as taught to the people by elders, and the importance of a unified set of values and beliefs of a culture as the basis for providing community support to families and individual with disabilities. We wonder about the wisdom of bringing in government money to solve problems where the

community is already so committed to providing support to its members without outside help. The villages need money for supports that cannot be provided in the community, and supports that they value such as infant learning and in-home parent training. Also, specific supports such as dollars for medical supports, transportation and per diem when travel is necessary for their children, etc. are needed and would be helpful to the community.

The needs are well stated by people in their stories, but we would be very careful to include tribal councils and people in local communities in planning for additional supports. This could probably best be accomplished at local villages, with some gatherings at Kotzebue.

With all of the needs that people talked about, there was an incredible sense of togetherness, humor and laughter, and strength in the people who participated. The people from the service system present were truly listening and have apparently been sensitive to the needs of the people. It seems that much more work could be done here to bring people together, and to work with people in villages to strengthen community connections between families, school personnel, etc. There is a new half time developmental disabilities program staff person who is beginning to do this.

Ketchikan

Friday, November 17, 1989 4:00 - 8:00 p.m.
Saturday, November 18, 1989 9:00 - 12:00 Noon

Purpose

The purpose of this meeting was to work with the group to define the parameters, organize the structure, and set up an initial meeting for a Parent Advisory Group to the school district.

Structure and Attendance

Participants included about 15 people: five mothers, representatives from the Infant Learning Program, the Governor's Council for the Handicapped and Gifted, teachers, Community Connections, director of special education, the superintendent of schools, and a school board member. There had been several previous meetings by sub-committees to draft a statement of purpose, goals and objectives, and by-laws. The two days were spent clarifying and rewriting these documents.

Forum Outcomes

The group agreed that the purpose of the parent advisory council is as follows:

> "The purpose of the Parent Advisory Council is to assist in the public interpretation and clarification of the laws related to exceptionalities and to advise the school board administration, staff, and the public."

After the group had clarified its mission, they spent the rest of the first day setting up primary goals that supported the mission and outlined the scope of activities they would engage in.

The group met the next morning for a period of three hours to outline the startup of the organization. Specific plans were outlined for the activities needed to gather other parents together to be members of the group, and to set the agenda for the first large meeting. Activities were planned, and people were designated to secure a meeting space and refreshments, get support and coordination from the school district for notifying parents, writing articles for the newspaper, doing a radio spot, networking with other parents informally to gather support, writing a cover brochure to give to people

that described the organization and secure a facilitator for the first meeting.

It was also decided that the first meeting would accomplish two objectives. First, to adopt the mission and bylaws and elect officers, and secondly to brainstorm activities for the rest of the school year. The group is well aware that it needs to have an action plan and have several small successes early in the process in order to show its stability and attract other parents to join the effort.

Facilitators' Impressions

1. It is difficult to write a lengthy report on this forum, because it was so action oriented. Community Connections saw an opportunity to use the forum as an opportunity to use outside facilitation to try and bring families and the school district closer together, which they identified as a primary need in the community.

2. As with most school districts and families, there is a history of mistrust and antagonism on both sides. Because of changes in administration in the school district, and a renewed commitment on the part of a core group of parents, it appears that there will be a collaborative effort resulting from this forum.

3. The school district is to be commended for clearly stating to parents that they supported a parents group, and, further, that they wanted it to be just a parents group and not a conglomeration of other special interest organizations so they could clearly hear what parents had to say.

4. The facilitator asked a school board member present at the forum to identify what help he would appreciate from the parents group. It was obvious from his comments that his desires were nearly identical to the goals of the parents group. This, obviously, is a good foundation for collaboration and cooperation between the two groups.

CIVIL RIGHTS

Kathy lives independently in an Alaskan city. She grew up in North Carolina where she went to a special residential school for people who experience physical disabilities. After finishing school she lived with her parents, who were alcoholics, and then spent eleven years living in nursing homes, nine years in North Carolina and two years in Alaska. For the past two years, Kathy has lived on her own in an apartment. She receives nine hours of personal care attendant (PCA) services a day and homemaker services once a week. She wants to be a writer and recently had her first article published. She attends the University of Alaska part-time and won a state sit-ski championship last winter. Kathy says that all modern guys are dweebs and that she doesn't believe in women's liberation. She has strong opinions about everything, including independent living, which she said is tough sometimes. Many people coming out of nursing homes or other institutions may need more support than is possible through current independent living programs. She believes that sometimes people are pushed into independent living situations before they are ready and that programs should find out how consumers are doing with independent living and perhaps develop a half-way program for people who need more support. Some members of her family still don't believe that she can live independently and attempt to control her life. Kathy believes that its impossible to predict what's in the future, she may decide to totally live her own life (with the help of PCA's) or she may decide to move back into the nursing home. Whatever the future holds, it will be Kathy's decision.

FACTS

1. There are 438 polling places in Alaska, of which 315 (72%) are rated as accessible, 100 are marginally accessible and 20 are totally inaccessible The number of accessible polling places is an increase of ten over the number accessible in 1986. Polling places that are marginal or unacceptable are primarily in rural or remote areas where accessible buildings are nearly nonexistent.

2. The federal Voting Rights Act of 1965, as amended, provides that any voter requiring assistance in casting a ballot may receive it from the person of the voter's choice.

3. The Federal Voting Accessibility for Elderly and Handicapped Act of 1984 promotes the right to vote to register and vote.

4. In Alaska, 22% of the adults interviewed for the Consumer Satisfaction Survey voted in the most recent election. The statewide voter turnout for that election was 69.5%.

5. According to the Consumer Survey, adults with disabilities possess a varying degree of choice in their lives. In Alaska, 37% chose their present living arrangement; 34% exercise control over their own money; 80% chose their friends and 77% determined what to do on weekends and evenings.

6. In 1988, Protection and Advocacy agencies for people with developmental disabilities across the country handled 58,312 cases.

7. The state's protection and advocacy agency, Advocacy Services of Alaska, provided services to 608 people with developmental disabilities, of whom 208 received direct intervention, during the same period.

8. More than half (51.4%) of the people interviewed for the Consumer Survey identified Protective and Legal Services as one of the community services they need. Two-thirds (67.5%) of these respondents report that they

currently have access to and are receiving these services. The most common reason cited for lack of service is that protective and legal services are not available in the area where the consumer lives.

9. In 1985, when the Public Guardians were transferred from the Alaska Court System to the Office of Public Advocacy within the Department of Administration, the staff consisted of 8 guardians serving 176 clients. There are currently only 6 Public Guardians for 346 clients.

CRITICAL ISSUES	RECOMMENDATIONS
1(a) Citizens with disabilities face discrimination in all sectors of their lives - jobs, housing, transportation, and recreation.	1. The Americans with Disabilities Act should be enacted during the 101st Congress as the main vehicle to secure and enforce nondiscrimination in the private sector and in state government activities.
(b) Many people do not perceive citizens with disabilities as potential voters or as a valid voting group.	The Governor's Council, Advocacy Services of Alaska and consumer groups should increase public awareness of discrimination and promote self-advocacy of people with disabilities.

Public Testimony Related to Item #1

"There's a very important difference between acknowledging the right of an individual to full access to public services versus relegating such access to a social services agency and the 'helping the handicapped' frame of mind." (Fairbanks Consumer)

Public Testimony Related to Item #1

"People with disabilities have many barriers to employment, as do other minority groups. Alaska has no affirmative action statement for people with disabilities as we do for members of other minorities." (Juneau Service Provider)

2.	People who live outside Anchorage, Fairbanks and Juneau have limited access to guardianship or protection and advocacy services.	2.	There should be a Public Guardian office in each of the state's four judicial districts. Public Guardians are currently located in Anchorage, Fairbanks and Juneau. A Public Guardian should be placed in Bethel as soon as possible. The Department of Administration should consider further regionalization of Public Guardians to such communities as Nome, Kotzebue, Barrow, Dillingham and Ketchikan, so that smaller communities in Alaska have equal access to guardianship.
3.	Most people who experience disabilities want to make choices about how they live their lives. Some program personnel view consumers, parents and guardians as incapable of making decisions.	3.	The Division of Mental Health and Developmental Disabilities should encourage and foster the development of new service approaches and service providing organizations so that consumers can choose among service settings and providers.

Public Testimony Related to Item #3

"In the past, it was up to us to decide what to do with our daughter. When people would ask, what will you do, what will she do, I could never answer. In the last year or so, Jylle has been telling us what she wants to do. It has taken me to task, because in the past I didn't really think she had the right or the ability to make a choice. Well, she has made a choice. She would like to live in an apartment. She would like to choose with whom she lives. I think she has the right to do that. (Fairbanks Parent)

4.	Alaska's guardianship law is considered a model statute by the American Bar Association. Due to understaffing and high client caseloads, the high standards set in the law are impossible to maintain.	4.	Additional Public Guardians must be hired immediately to bring individual caseloads down to 30-35 clients per Public Guardian. This would require five new positions for Anchorage and one each for Juneau and Fairbanks. Public Guardians must receive orientation and on-going training on disabilities issues and be prepared to provide assistance to private guardians. In addition, they must give priority to identifying family members and friends who, with advice and support, would be willing to be guardians of individuals with disabilities.

5.	Becoming a guardian can often be an expensive undertaking. Under the current practices and rules of the court, a family member who wants to become the guardian for a person who experiences a disability usually must hire an attorney to initiate the process. Guardianships for people living in institutions and for young people under the supervision of the Division of Family and Youth Services are paid for by the state.	5.	The Department of Administration and Advocacy Services of Alaska, in consultation with the Governor's Council, should publish a guide for people wishing to become guardians that makes the process more understandable and provides information on how to initiate guardianship proceedings and , if necessary, the statute should be revised to be more "parent friendly".

Public Testimony Related to Item #5

Natural parents who need to be declared guardians of one of their own children, as we did, so that our son could be accepted at Harborview, can be treated very badly by Alaska's "model" guardianship statute and the regulations and procedures it gives rise to. It cost us about $1,500 in lawyers fees. We had to appear in court with counsel, sitting opposite our son's appointed lawyer. Even though the judge apologized for the whole thing, that doesn't make you forget the grotesque and insulting situation. And it is impossible to forgive or forget the fact that the court appointed "visitor" was told that she had to ask our other three children, individually, whether or not they thought we were "good parents". We were trapped; how could we refuse with the implied threat that we might be refused guardianship of our own son? (Fairbanks Parent)

6.	People who experience disabilities have limited access to state funded health, social service or training programs. Program facilities may be physically inaccessible, administrators unwilling to provide adequate sign language interpreting services or operating procedures which are not flexible enough to meet the needs of people with disabilities.	6. The state should enforce regulations that require that state funded programs be conducted from accessible buildings and provide adequate interpreter services to people in "treatment" programs.

Public Testimony Related to Item #6

"Full interpreting assistance is needed for alcohol and drug abuse treatment and self-help groups for the person and the family affected by alcohol and drugs. How can someone recover when they are denied access to the very communication they need in order to get well?" (Fairbanks Consumer)

EDUCATION

This year, Andy, a six year old first grader, moved from a special program and school for students who experience orthopedic impairments, to a regular classroom in his neighborhood school. He is the only child with multiple handicaps at the school and it has taken a great deal of negotiation and collaboration on the part of his parents, the teachers, the principal, and district special education personnel to make the change work for Andy and his school. Many thought that he needed too much to be in a regular classroom and that regular education students in the class would be neglected as a result. Teachers felt they needed more training and support in order to make mainstreaming work. Scheduling of resource services for Andy was also a problem. Initially, he was being pulled out of the classroom on a schedule that disrupted both the classroom and Andy's regular education program. With collaboration from all parties, his schedule was revised to allow him longer periods of time in his regular classroom and fewer disruptions for his classmates. Reflecting on Andy's experiences with mainstreaming, Andy's mother thinks that regular education teachers need more preparation prior to the integration of a child with special needs into the classroom. One important step would be to ask teachers what they need on an ongoing basis. She thinks that what they might ask for may not always be what special education personnel expect. While there are still adjustments to be made, Andy's is thriving at his new school.

FACTS

1. The Infant Learning Program of the Division of Public Health provided early intervention services to approximately 900 children from birth through two years old during F89. These services are delivered in the child's home and focus on assisting the parent to be the child's primary teacher.

2. Infant Learning services are not available to families in the Doyon Region and the Copper Center area. There are approximately 100 children in these areas needing services.. Statewide, there are currently over 200 children on waiting lists for infant learning services. Many other parts of the state are underserved, which means that children receive fewer teacher visits and other therapeutic services than they need.

3. During the 1988-89 school year, there were 14,684 children between the ages of 3 and 22 receiving special education services in Alaskan schools. More than half (52%) of the students have learning disabilities. Other students have mental retardation (15%), hearing impairments (less than 1%), deafness (less than 1%), speech impairments (23%), visual handicaps (less than 1%), emotional disabilities (4%), orthopedic impairments (less than 1%), health impairments (1%), deafness and blindness (less than 1%), multiple handicaps (3%), and developmental delays (2%).

4. Consumers interviewed as part of the Consumer Survey were generally positive about the educational services they received. At least 70% of the people interviewed said they were satisfied with the following educational services; infant learning (72%), preschool (76%), regular class with resource room (77%), and special class in a regular school services (82%) they received. The most common reasons for dissatisfaction were that they were not receiving enough (early intervention and resource room) and that the programs were not suited to individual need.

5. Parents interviewed as part of the survey were the most dissatisfied with educational services if their child was in a regular class in a regular school. Only 32.5% indicated that they were satisfied with this setting, most commonly because it was not suited to the individual needs of their child. The main reason for this was that necessary training and support was not available to the classroom teachers.

6. The educational services most urgently needed by people interviewed for the survey were preschool services for children with emotional disabilities, afterschool tutors, and summer school programs. The most common reason that children were not receiving these services is that the services are not available in their communities.

7. Of the children between the ages of 6 and 22 interviewed as part of the Consumer Survey, 12% have received most of their education in a separate day school. In contrast, 32% of those interviewed who were over 22 years old spent most of their years in school in separate schools. The proportion of children receiving their educations in special classes in regular schools has increased from 30% for those over 22 to 58% of those between 6 and 21.

CRITICAL ISSUES	RECOMMENDATIONS
1(a) Most students with severe disabilities continue to be segregated from other students in public schools. They are denied opportunities to participate in age-appropriate, integrated learning environments with non-handicapped peers.	1. The Alaska Board of Education should require that all districts develop a plan for full inclusion of students whoexperience disabilities, including:
(b) There is significant research evidence that educating students with special needs in the regular classroom is more beneficial than using segregated environments provided that specific and intensive services are provided as needed.	• providing all special education programs in integrated age-appropriate school settings; • a community - based, functional curriculum that prepares students for full community participation. • encourage regular collaboration between regular and special education staff and programs within school districts.

2.	Research and parent input verify that many children in special education programs lose skills gained during the school year over the summer without summer programs.	2. The Department of Education should ensure that all Alaskan school districts provide meaningful summer programs for special education students who need such services to maintain gains made during the school year.
3.	All districts count special education students in regular school enrollments and receive regular education foundation support for them. Special education funds are generated in addition to those regular foundation funds and are to be used to provide the special education services handicapped students require. Many districts do not spend all these funds to benefit special education students while some provide significant local funds in addition to foundation funding for this purpose.	3. The Department of Education should require and enforce that local district accounting systems charge actual special education expenditures to special education accounts so that advocates can work at the local district level to insure funds are spent where needed.

4.	The quality of preschool programs varies greatly around the state. Some districts offer only minimal programs while others have a variety of settings, including regular half-day programs. The services a preschool child receives are often dependent on where the child lives rather than what he needs. There are virtually no pre-school services available to children with emotional disabilities.	4.	The Department of Education should provide technical support to school developing screening and evaluation methods and preschool services for children with emotional disabilities.
5.	There is a shortage of certified special education teachers in rural areas, with the shortage of specialists (physical, occupational and speech therapists) even more critical. Children in rural and remote areas receive specialized services less often than children living in urban areas.	5.	The state should support the development of in-state training programs for physical, occupational and speech therapists or alternative out of state programs that offer incentives for people to become therapists and return to Alaska. At the same time, the state should create mechanisms to train, legitimize and support paraprofessionals in providing specialized services in rural and remote areas.

6. Special Education teachers in rural areas are often responsible for serving all handicapped and gifted/talented students, regardless of the student's age, exceptionality, or intensity of program. These teachers are rarely trained in more than one area.	6. Funding should be increased to reduce teacher/pupil ratios and provide training and support to regular and special education teachers who serve multiple grade levels and a wide range of exceptionalities.
7. Assessment tools and measures are biased and inappropriate for children who are bilingual. There is currently no method of determining the child's language proficiency prior to assessment.	7(a) The Special Education staff and Bilingual staff at the Department of Education should develop a means of assessing students for language proficiency. (b) The Department of Education should provide technical support to school districts in developing culturally and language appropriate screening and evaluation methods.
8. Many young people who experience disabilities graduate or finish school unprepared to enter the world of work. Many have insufficient or no vocational education services as part of the IEP.	8. Planning for the transition from school to work should involve the parents and the private sector and should become a part of the IEP by the time the student is fourteen years old. Transition planning in rural areas must be compatible with the subsistence life- style and/or cultural differences of the area.

9 . Parents are generally the best sources of what's right for their child. Parents are also most effective in providing support to other parents. Parent counseling and training is an allowable expense for related services under P.L. 94-142.	9. Parent education and support groups should be encouraged and financially supported by the Alaska Department of Education and by each school district and the state Department of Education and recognized as an allowable special education expenditure under related services..
10. Under P.L. 99-457, educational services for children under the age of three will become an entitlement. It is unclear how these services will be funded and how the services will be extended to currently unserved and underserved areas of the state.	10. The Alaska Legislature should fully fund Infant Learning Programs. State legislators should be urged to adopt the program as an entitlement program and provide sufficient funds to eliminate all waiting lists.

Public Testimony Related to Item #10

"There are three (Infant Learning Program) teachers to cover 43 villages in our region. We find that impossible to do." (Bethel Infant Learning Program Teacher)

11. The Alaska State Program for the Deaf in Anchorage provides educational services to school-age children who experience deafness. Children from rural areas of the state must leave their home communities and live with foster families in Anchorage if they are to attend the school.	11. The Department of Education should work with rural school districts, the State Program for the Deaf, the Special Education Services Agency and parents to develop educational and support options for children who experience deafness.

EMPLOYMENT

Jack was living in California is the early 1980's when his brother in Anchorage became concerned by reports that Jack was not attending his sheltered workshop program on a regular basis. On checking out the situation, he learned that the home where Jack was living was not providing sufficient care and, in fact, was an abusive situation. He brought him back to Alaska and contacted the Client Program Manager of Division of Mental Health and Developmental Disabilities for assistance in finding services and supports. Jack was initially placed in a sheltered workshop and then, in 1982, became one of the first Alaskans to work in the community through supported employment. Jack has worked for seven years at Sadler's Furniture doing general janitorial work. He is currently working 20 hours a week and earning $4.50 an hour. He worked more in the past but a combination of the economic slowdown and restrictions on how much he can earn before losing his SSI benefits prevent him from increasing his hours. The company he works for is a family operation and Jack is a member of the "family" of employees. He takes part in all company activities and his fellow employees consider him a valued co-worker. He receives minimal support from the vocational program, usually only a visit to the job site once a month. Jack has continually progressed in acquiring new job skills and is thriving in the community.

FACTS

1. Two-thirds of all Americans with disabilities, between the ages of 16 and 64, are not working. NO OTHER DEMOGRAPHIC GROUP HAS SUCH A SMALL PROPORTION WORKING. Two-thirds of unemployed Americans with disabilities want to work, and could be working, with supportive services.

2. Nearly two-thirds (65%) of the Alaskans with disabilities interviewed for the Consumer Survey are currently not working. More than a third of the adults (35%) interviewed had never worked.

3. Barriers to employment often cited include prejudicial attitudes towards people who experience disabilities and their abilities; under-education and lack of marketable skills; lack of accessible or affordable transportation; lack of needed equipment or devices to help them work or

communicate; and fear of loss of key benefits, such as government health insurance. BUT, in a Harris Poll, only 18% of the Americans with disabilities interviewed who were not working or working part-time, said that fear of loss of benefits is an important reason why they are not working fulltime.

4. In the Consumer Survey, 54% of those interviewed were satisfied with vocational education programs for school age children. The most common reason for dissatisfaction was that students were not receiving enough vocational education.

5. Alaskans interviewed for the survey were generally satisfied with the vocational options currently available, including work activities or prevocational programs, facility based sheltered employment, and supported employment. The main reason for dissatisfaction noted was that they were not receiving (working) enough.

6. People working in the competitive labor market were the most satisfied (85%) with their vocational or employment situation.

7. Approximately 75% of the people employed in programs funded by the Division of Mental Health and Developmental Disabilities are working in supported employment settings (enclaves, work crews, bench works and supported jobs) or competitive employment.

CRITICAL ISSUES	RECOMMENDATIONS
1. Many young people who experience disabilities graduate or finish school unprepared to enter the world of work. Many have insufficient or no vocational education services as part of the IEP.	1. Pre-vocational planning and educational services for eligible students enrolled in special education should begin no later than when the student is twelve years old and be community based.
2. People with disabilities often only have access to entry level positions with little opportunity for career advancement.	2. All individuals should be provided the opportunity for career advancement based on their skills and abilities and without regard to disabilities. The Governor's Council should increase public awareness activities about the abilities and employability of people with disabilities.
3. Transportation and attendant services are not consistently available when needed by people with disabilities seeking or attempting to maintain employment.	3. The Alaska Division of Medical Assistance should expand the availability of personal care attendant services to people who experience disabilities who need this support to work and should encourage incentives to employers.

4. People who experience severe physical disabilities or behavior problems often remain in sheltered workshops rather than finding placements in community based work settings.	4(a) The state and federal government should provide funding of the ongoing support needed for individuals who require those supports to maintain gainful employment in the private sector. (b) People need options in the public and private sector. Positions within the Alaska state government personnel system should be opened to supported employment placements and state employment should provide means for advancement for employees who experience disabilities.

Public Testimony Related to Item #4

"We have job opportunities out here in the Valley that will employ people but we do not have the resources to develop the jobs or train the workers or supply the long term support that many people with developmental disabilities need to maintain their employment." (Wasilla Service Provider)

"We have job opportunities, we have individuals who want to work, but without additional funding none of these individuals will be provided with the opportunity for work." (Valdez Service Provider)

"Supported employment is a must. We spend a lifetime building up our children's self-esteem, telling them they can do things, and when they graduate, it's as if the rug is pulled out from under them." (Anchorage Parent)

5.	New developments in adaptive devices and equipment are often costly and therefore not always available to people who experience disabilities. Medicaid and Medicare, rehabilitation agencies, insurance companies, etc. are often reluctant to fund newer, more technologically advanced, and more expensive items.	5.	The Division of Vocational Rehabilitation (DVR), with the assistance of the Department of Education, private providers and support groups, should continue to pursue funding for a statewide system for the provision of adaptive equipment that would serve all Alaskans needing this service, not just those in school or eligible for DVR services. The Governor's Council should work with the Division of Medical Assistance and the Division of Mental Health and Developmental Disabilities to develop a family subsidy program to provide financial assistance to families to purchase chase and maintain needed adaptive equipment, home modifications, and specialized resources.
6.	People who experience a disability due to injury or illness while employed by the state are not provided adequate opportunities for re-employment by the state.	6.	Alaska statutes that provide for the rehire of employees who were terminated because of illness or injury on the job should be fully implemented by the executive branch of state government.

HEALTH CARE

In 1974, at the age of nine, Bonnie was accidentally shot in the neck, resulting in quadriplegia and respirator dependence. Through a combination of tutors and part-time attendance, she finished grade school. By junior and senior high she was able to spend the entire day at school. Bonnie enrolled in a five-year college program and finished in four years, receiving her degree in psychology from the University of Alaska Fairbanks. In August of 1988, Bonnie moved out of a nursing home and into her own apartment. In September, she was dropped from the Medicaid personal care attendant program. She needs 15-1/2 hours of personal care each day. Advocacy Services of Alaska was able to have her temporarily reinstated in the program in February, 1989. In the interval, Bonnie's family and friends helped her remain independent. Bonnie won a full scholarship for graduate studies in rehabilitative counseling in Urbana, Illinois, and in August, 1989, moved into a small apartment one mile from campus. With help from the Division of Vocational Rehabilitation, Upjohn Health Services of Illinois agreed to provided personal care attendants to Bonnie, to be paid by the Medicaid program in Alaska. But the Division of Medical Assistance asked Upjohn to discontinue attendant services because the attendants were not certified in Alaska and did not have Alaska business licenses. Currently, the Division of Vocational Rehabilitation is paying for Bonnie's personal care until her Medicaid appeal is decided. No matter what the outcome, Bonnie says she will not return to a nursing home. She will continue her effort to lead a normal, productive existence, free of institutional restraints. (Paraphrase of biographical sketch included in 1989 Victory Awards brochure)

FACTS

1. Approximately 85% of Americans covered by health insurance obtain it as a fringe benefit of employment.

2. In 1985, approximately 46,100 Alaskans had no form of health care coverage - public or private.

3. Most private insurance companies either refuse to insure or will limit coverage for persons with pre-existing health conditions (e.g. people with disabilities).

4. Services such as physical, occupational and speech therapy; medical equipment and supplies; and home health care are the least likely to be fully covered by public or private funding, require higher co-payments than other services, and are subject to more limitations than inpatient services.

5. Some funding exists for assistive devices (such as adapted toys, computers, communication devices, powered wheelchairs, environmental controls, and ramps and other modifications made to the home to make it more accessible), but much of it is tied to specific purposes or activities (e.g., education or rehabilitation) and is subject to age, income, type of disability or other eligibility requirements. Some equipment may also be so expensive as to be out of reach for all but a few families or organizations.

6. Native Alaskans receive health care through the Indian Health Service of the U.S. Public Heath Service (PHS). Health care is provided by Community Health Aides in villages and smaller communities, PHS or native corporation hospitals and clinics in larger communities, and at the Alaska Native Medical Center in Anchorage.

7. Military personnel in Alaska are covered by military health insurance (CHAMPUS) and receive most medical services at fort/base clinics and hospitals.

8. In 1984, Medicaid, nationwide, provided payment for services for less than 40% of the poor.

9. Nationally, Alaska ranks 34th in the percentage of state population receiving Medicaid benefits. Nationally, 8.6% of Americans receive Medicaid services while in Alaska 5.4% receive these services.

10. Alaska and Wyoming are the only two states which do not operate any type of Medicaid waiver program and/or a categorically needy program for children with disabilities. A waiver can provide 50% federal funding to support community services that are now 100% state funded.

11. The number of Alaskans receiving extended Medicaid services through the Section 1619(b) program dropped from 41 in September '87 to 34 in September '88.

12. States have a high degree of discretion related to how Medicaid option services are defined and delivered. For personal care services, the state of New York had a per capita expenditure in F87 of $46.86 and Alaska spent 58 cents.

CRITICAL ISSUES	RECOMMENDATIONS
1. Alaska is one of the most conservative states nationally in its use of federal Medicaid funding. Because Medicaid plays a major role in funding service for people with disabilities there is a strong institutional bias in services available to Alaskans who experience disabilities.	1. The Department of Health and Social Services should pursue Medicaid options and waivers that will provide community alternatives to institutional care for people who experience disabilities. Options that may have positive impacts on people who experience disabilities are case management, extending categorically needy eligibility to all qualifying children with disabilities, "home and community based" waivers and "model" waivers. The purpose of a waiver is to provide Medicaid funded community based alternatives to institutional care. The federal government will pay 50% of the costs of approved programs.

2(a) Most private insurance is tied to employment and many people who experience disabilities have difficulty finding employment.	2(a) Legislators, state officials and consumers should actively support the Basic Health Benefits for All Americans Act of 1989 (S.768) which requires all employers to provide health insurance to their employees and dependents. (Kennedy (D-MA) sponsor)
(b) Since many people with disabilities are employed in marginal jobs with no fringe benefits, lack of health care coverage is a particular concern for this group.	(b) The federal Congress and/or the Alaska Legislature should create financing mechanisms that ensure that people who experience disabilities, and who are not insured in the private sector, are provided with insurance and have access to the medical services they need.
3. The Handicapped Children's Program, a major payment source for families who are not eligible for Medicaid and who do not have sufficient insurance coverage, has a $20,000 limit on reimbursement and does not cover children with certain conditions, such as cancer and prematurity.	3. The Department of Health and Social Services should remove the $20,000 limit on reimbursement through the Handicapped Children's Program and expand coverage to include all children with disabilities in an equitable manner.

4. Section 1619(b) provision of the Social Security Act, which is intended to allow people to "take a risk" with employment opportunities without fear of losing medical coverage, is clearly underutilized in Alaska. The state had the second lowest percentage of state population (.4%) receiving SSI benefits nationally. The national average in 1985 was 1.1%. Only those receiving SSI benefits are eligible for Section 1619(b) participation.	4. The Division of Vocational Rehabilitation, the Division of Mental Health and Developmental Disabilities, and the Social Security Administration should work jointly to develop methods to encourage fuller utilization of the Section 1619(b) program.
5. Since people with disabilities obviously have "pre-existing conditions", their lack of insurability by private companies is a major problem. Most major insurance companies provide the opportunity to purchase coverage to all applicants, but the cost may be so high and/or the coverage so limited as to render it totally unaffordable or inadequate for people who experience disabilities.	5(a) Legislators, state officials and consumers should actively support the Med-America Act of 1987 (S.1139) which would allow states to provide Medicaid coverage to people with pre-existing conditions regardless of their income who are rejected by private insurers. (Chaffee (R-RI) sponsor) (b) Legislators, state officials and consumers should actively support the Federal Health Insurance Equity Act of 1989 (H.R.2649) which would prohibit insurers from excluding, terminating, or otherwise limiting any individual from coverage based on a pre-existing condition. (Walgren (D-PA) sponsor)

6.	Funding for assistive devices is very limited in Alaska. It is usually tied to services through the Division of Vocational Rehabilitation or through special education programs in the school districts. The ELKS HELP program advises people in the selection of adaptive equipment and loans out devices for trial use, but the eventual purchase of the device is often up to the individual.	6.	The Division of Vocational Rehabilitation (DVR) should continue to pursue funding for a statewide system of providing assistive technology to all Alaskans who need it. DVR has submitted a proposal for funds available under the Technology-Related Assistance for Individuals With Disabilities Act of 1988, P.L. 100-107.
7.	The personal care option is the only addition to the mandatory Medicaid program offered by the state. Consumers report that the state will need to increase the number of personal care hours allowed in order for this to be a viable alternative to institutionalization.	7.	The Department of Health and Social Services should increase the number of hours of personal care attendant services available to consumers.
8.	Because there are multiple health care systems in the state, coordination is a major issue and the possibility of people falling through the cracks between systems is a continuing concern.	8.	A statewide health care provider organization should be formed to coordinate Alaska's multiple health care systems on an ongoing basis. At a minimum, this group should include representatives from state government, the Indian Health Service, regional health corporations, military providing private hospitals, nursing homes and private physicians.

HOUSING

Michael (not his real name) lives in an Alaskan institution. He was born in a small village in Western Alaska, was placed in the institution as a child, and is now in his twenties. Michael is a "behavior problem" at the institution. He experiences incontinence three or four times a month, abuses others an average of every other day, but mostly abuses himself by banging his head and scratching his face until it bleeds (an average of 73 times a month). As a result he is given 150 mg. of Mellaril a day for "behavior therapy". During the summer of 1989, Michael had the opportunity to stay with a friend in a community 300 miles from the institution. He became drug free in July and visited his family in the village in August. This visit was the first time he had been home to see his family in ten years. Over his three month visit, his incontinence disappeared and the incidents of abuse decreased to less than once a week. He was out in the community everyday doing a wide range activities. Due to lack of further state funding, Michael returned to the institution at the end of the summer. It costs $300 ($150 of which is paid by the federal government through Medicaid) a day to keep Michael in the institution. It would cost the state approximately $100 a day to provide the supports he needs in the community.

FACTS

1. Nationally, 25 to 30 percent of people who experience disabilities report housing difficulties, including problems with access, physical structures and neighborhoods. A national study found persons with cerebral palsy, spinal cord injuries, multiple sclerosis and seizure disorders among those with high levels of dissatisfaction with their living arrangements.

2. Since the early 1970's, the number of people living at Harborview Developmental Center, Alaska's institution for people with developmental disabilities, has been slowly dropping. In 1978, there were 105 people living at the Valdez facility. There are currently 57 people residing there, none of whom are children.

3. As the demand for institutional placements dropped, the Division of Mental Health and Developmental Disabilities funded more less restrictive setting for people with developmental disabilities.

	1978	1989	% Change
Shared Care	0	9	-
Specialized Foster Care	23	42	+91%
Apartment Programs	0	11	-
Independent/Supported Living Programs	0	83	-
Group Homes	86	145	+69%
Harborview Developmental Center	105	57	-46%

4. In 1978, there were 32 people with developmental disabilities living in nursing homes in Alaska. This number rose to 62 in 1982 but has dropped back down to 32 in 1988. There are currently twelve children under ten years of age living in the state's nursing homes.

5. There are 320 people on waiting lists for community residential services from the Division of Mental Health and Developmental Disabilities (DMHDD).

6. There are no developmental disability program standards or monitoring systems in place to assure the quality of community residential programs funded by the DMHDD.

7. Three percent (3%) of the people interviewed for the consumer satisfaction survey received HUD Section 8 Rent Certificates. Another 3% had applications pending for rent certificates.

8. Eight percent (8%) of the people interviewed for the survey owned their home of held the lease for their house or apartment.

9. People who experience disabilities who were interviewed for the consumer satisfaction survey live in a wide range of housing options:

Single family home in a neighborhood	52%
Multi-family home or apartment in a community setting	24%
Single family home in a rural area	9%
Institution	7%
Living facility specifically built or extensively renovated that would only be suitable for use as a congregate care facility	5%
Rooming house or residential hotel	2%
Nursing home	1%

CRITICAL ISSUES	RECOMMENDATIONS
1. Affordable housing is a problem for most low income people, including people who experience disabilities. Accessible, barrier-free, affordable living arrangements are scarce and in high demand.	1. Accessible, affordable housing options for people who experience disabilities need to be expanded. Housing policy goals for people with developmental disabilities should: • Focus on supports, environmental adaptations, and housing characteristics selected by the individual and tailored to individual needs; • Empower individual adults to own or rent their own homes; and • Ensure that children live in a family home.
2. Newborns who are "medically fragile" or "technology dependent" often spend extended periods of time during their first months living in neonatal intensive care units or nursing homes. Newborns from the rural areas of Alaska often spend the first two or three years of their lives there, waiting for placement in an urban foster home.	2. The Department of Health and Social Services should work with regional health corporation hospitals to increase their capacity to admit infants who are "medically fragile" or "technologically dependent" into skilled nursing "swing beds" in their hospitals. This would allow more frequent contact between the child and family.

3. Residential options are nearly nonexistent in rural areas of the state. People from these areas must leave their home community, family and culture to get the services they need in an urban setting.	3. The Division of Mental Health and Developmental Disabilities and the Governor's Council for the Handicapped and Gifted should continue to foster the development of community services in rural areas.
4. Medicaid reimbursement has an institutional bias. Because Alaska has not sought waivers, Medicaid funds cannot be used to fund community based services.	4(a) Division of Medical Assistance should seek Medicaid waivers to fund community residential programs for people who experience disabilities. (See Recommendation #1, Health Care Section)
	(b) The implementation of the new ICF/MR regulations and P.L. 100-203 (nursing home reforms) should be carried out in ways that promote the use of community housing and program alternatives rather than increased resources dedicated to institutions.

Public Testimony Related to Item #4

"I don't want people with disabilities living in nursing homes or API (Alaska Psychiatric Institute). They need to live out in the community, just like the regular people and have regular jobs. I don't want them to suffer in nursing homes and I want them to stop putting them into institutions." (Anchorage Consumer)

"There is currently no program for families who choose to keep their children in their homes. You certainly can have state funding if you chose to institutionalize your child. Those of us who chose not to do that receive no type of financial support and, when we need services, it's very difficult." (Anchorage Parent)

INCOME

In many ways, Holly is a success story. Through persistence and planning on her mother's part, Holly moved into a group home the year before she finished high school. When she left home to live in the group home, she signed up for SSI and received maximum benefits. After she finished high school, she was hired by a local clothing store, where she's worked for almost a year. After working some overtime, she notified the Social Security Administration of her increased earnings. Three months later she received a notice that she had gotten an overpayment and that, unless she paid it back immediately, it would be taken out of her monthly SSI check. Holly is working 20 hours a week for $5 an hour. Any reduction in her SSI check makes it difficult to make ends meet. And if she loses her eligibility for SSI, she will no longer be eligible for Medicaid and probably wouldn't earn enough money to pay rent and other expenses at her group home. Holly's mother is especially frustrated because she feels that the government is forcing Holly to maintain a poverty standard of living. Holly is capable of and eager to work more but can not afford to with current SSI policies.

FACTS

1. Half of all Americans who experience disabilities, aged 16 and above, have a household income for 1984 of $15,000 of less. Among non-disabled Americans, only 25% are in this income bracket.

2. The Social Security Administration uses the Substantial Gainful Activity (SGA) level to set the amount of earning from employment needed to establish that a person no longer has a work disability. The SGA level for non-blind recipients of Supplemental Security Income (SSI) is currently $300 per month, and has remained at that level since 1980. This is $150 less per month than the poverty level (1986) and $276 less per month than the minimum wage.

3. The Substantial Gainful Activity amount for blind Social Security Disability Insurance (SSDI) recipients is currently $740 per month (1989) and increases annually.

4. Section 1619(a) and (b) of the Social Security Act are work-related provisions that provide incentives to employment and allow people with disabilities to try to work without risking loss of income support and/or other benefits of Supplemental Disability Income. They are not available to recipients of Social Security Disability Income.

5. More than 70% of those interviewed for the Consumer Survey said that they needed income assistance. More than a third (35%) of the consumers needing assistance are not receiving it, primarily because they are ineligible because of income or means.

CRITICAL ISSUES	RECOMMENDATIONS
1. People interviewed for the Consumer Survey said that they wanted to work more hours than they do currently. The low Substantial Gainful Activity (SGA) level for Social Security restricts many people from working to their full potential for fear of losing the income protection and other benefits associated with SSI and SSDI benefits.	1. In order to promote equitable treatment for people with similar disabilities, Congress should pass legislation which would make Section 1619(a) and (b) available to SSDI recipients.
2. The $300 SGA limit for SSI is inequitable when compared with SGA for blind recipients of SSDI, the poverty level, and minimum wage levels. The SGA level does not reflect the income needed to achieve reasonable self-sufficiency in the community.	2. SGA levels should be increased for all SSI and SSDA recipients to the level currently received by SSDI blind recipients ($740).SGA levels should increase annually to compensate for inflation.
3. With the increase in supported work options, more people who experience disabilities are working more hours at minimum wage or better.	3. The Social Security Administration should develop policies to deal with income earned from supported employment.

INDIVIDUAL AND FAMILY SUPPORTS

Logan is eight years old and lives with his parents and older brother in a small community in southeastern Alaska. A year ago, the family was in trouble. Logan's mother contacted the local program requesting shared care for Logan. She says that once it became apparent that the family might break up, "..services fell from the sky." Although Division of Mental Health and Developmental Disabilities (DMHDD) services were not immediately available, the family received crisis homemaker services through AMTECH. Within six months, a "family specialist" was funded for the family. The specialist started by sitting down with each family member to talk about their concerns and to find out what kinds of immediate action could be taken to eases the stresses felt by the family. Together, the family and the specialist devised a program for Logan that included a summer activity of going to the playground each day to spend time with other children his age. During the school year, the specialist goes to child study team meetings with the family and spends times observing Logan's school program. She helps recruit and train the family's respite providers, helps with the necessary paperwork, and is available for advice at any time. Logan's family is extremely happy with the support.

FACTS

1. Fifty-six percent (56%) of Americans who experience disabilities say that their disability prevents them from getting around, attending cultural or sports events, or socializing with friends outside their home as much as they would like.

2. Mass transit is available in only three Alaskan communities - Anchorage, Fairbanks and Juneau. Each of these communities also has a para-transit system that provides door-to-door transportation for people who experience disabilities.

3. In the Consumer Survey, 39% of those interviewed said that they needed adaptive equipment or, assistive devices or training to live in the community. Of those not receiving these services, the most common reasons were that the service was not available in their community or that it was too expensive.

4. People interviewed for the survey said that the services with which they were most satisfied were home health aides and visiting nurses (87%), and income assistance (SSI) (81%).

5. The support services with which consumers were most dissatisfied were companion/friend-advocate programs (50%), family supports groups (33%), family counseling (39%) and mental health or counseling services (40%) because they were not available in many communities. Parents were also dissatisfied with child care programs (39%) because they are not suited to the child's individual needs.

6. Centers for Independent Living (CILs) are available in two Alaskan communities; Anchorage and Fairbanks.

7. More than half (57%) of the people interviewed for the Consumer Satisfaction Survey said that they receive case management services although it is unclear who is providing the services and what they entail. A high percentage (78%) of consumers say they need case management and that the most common reason that they don't receive it is that it is not available in their area.

8. Approximately 400 people received respite services funded by the Division of Mental Health and Developmental Disabilities during F89. There is a wide variation in the number of hours of respite families receive. Some program are able to provide families up to 40 hours of respite per month. There are also programs where parents only recieve 4 hours of respite per month because of the high demand for the services.

9. There is currently only one program in Alaska that provides home modifications to consumers. This project is a collaboration between ACCESS Alaska in Fairbanks (a Center for Independent Living) and the Carpenter's Union.

10. In 1986, one third of the child care centers in Alaska reported that they denied admission to a child who experienced a disability. The most common reason cited was lack of care giver training and inaccessible facilities.

11. None of the television stations in Alaska provide closed captioned local news. Locally produced specials on Alaska, including "Jay Hammond's Alaska" are also not closed captioned.

CRITICAL ISSUES

1. Many programs still focus on making the person fit the program rather than the program fit the person. People are often relegated to services that are more intense and restrictive than is necessary, limiting a person's ability to be as independent and as integrated in the community as possible. Families feel strongly that programs do not meet their individual needs.

RECOMMENDATIONS

1. Supports to people with disabilities should promote independence, productivity and integration and embody the following principles:

   a. maximum consumer control and direction;

   b. priority for community based services;

   c. availability to people in all areas of the state, of all ages and with all types and levels of disabilities.

   d. individually determined to meet the unique needs of the family and the community in which they live.

2.	Parents are the best sources of what's right for their child. Parents are also most effective in providing support to other parents. Part of empowerment of families means recognizing parents as valued members of the "service system".	2.	Supports to families which include a member who experiences a disability should be designed to meet individual needs and emphasize supports that: a. involve families in the design, implementation and monitoring of family support systems. b. reinforce the primary role of families in proving care and support; Furthermore, a long-term, stable interdepartmental funding base should be established to support parent and primary consumer, groups, and family support networks.

Public Testimony Related to Item #2

"There is a need across the state for monies to be appropriated to help parent groups provide resources and support for one another at the local level." (Soldotna Parent)

3.	While many national news and entertainment programs are closed captioned, only one Alaskan television station provides closed captioned local news and few Alaskan specials are captioned.	3. All television programming produced with state support should include high quality closed captioning.

Public Testimony Related to Item #3

"We need the local news in Fairbanks closed captioned. And like, "Jay Hammond's Alaska" on TV... it's a very great picture but I can't hear what's going on. I'd like to know what's going on." (Fairbanks Consumer)

4.	Weather issues make Alaska a logical location for testing of all types of assistive devices. To date, little or nothing has been accomplished toward making assistive devices operable in cold weather climates.	4. Alaska should become a cold weather test site for lifts and other devices essential to making mainstream transportation accessible to people with disabilities
5.	Access to Alaskan state parks is extremely limited for people who experience disabilities, especially mobility impairments.	5. The state should join in a partnership with people who experience disabilities to explore ways to make state parks more accessible. This will benefit others who use state parks, such as older Alaskans, families with young children, inexperienced hikers, etc.

6.	Child care is expensive and difficult to find for families with children who experience disabilities. This is especially true for school age children who need before and after school care.	6.	The Alaska Department of Community Community and Regional Affairs currently offers grants for training child care workers in various skills, including working with children who experience disabilities. The Department should expand these efforts to include funding of specialized equipment, low interest loans for renovations to child care facilities to improve accessibility, and methods of supplementing the salaries of child care workers who acquire specialized skills for working with children with disabilities. In addition, consumers and advocates should work at the local level to increase the capacity of local child care centers to serve children who experience disabilities.

SYSTEMS ISSUES

Rob is twenty-three years old and lives in an Alaskan city. During his last few years in high school, Rob had the opportunity to try out a number of jobs through the vocational education program, including watering plants in a greenhouse, vacuuming for a local business, collating materials and, his favorite, busing tables in a cafeteria. Now that he's finished school, he wants to move into an apartment, find a job and be independent, like his younger brother. Planning for his future, Rob's parents had his name Developmental Disabilities waiting list six years prior to his graduation from high school. Six months after graduation, Rob is still sitting at home. He is lucky to live in a city with an activity center where he goes each day for social and recreational activities, but what he really wants is a job. His mother said that initially he was glad to be out of school because there were many things about school that he did not like. Now, Rob wants to go back to school so that he can have his old job back.

FACTS

1. It is estimated that up to 300 young adults graduate from Alaskan schools each year who need some level of community living and employment support following graduation.

2. There are no program standards or monitoring systems in place to assure quality of community residential and vocational programs funded by the DMHDD.

3. There are currently approximately 320 people waiting for residential, vocational and in-home support services provided by the DMHDD.

4. The Alaska DMHDD uses a categorical definition of developmental disability. The Infant Learning Program, Special Education, Handicapped Children's Program, and Medicaid use a wide range of definitions to determine eligibility for services.

5. There is no common method of collecting information on clients and services used by people who experience disabilities. Some programs have long standing computerized information systems while many others are still us-

ing paper systems that make analysis of service information difficult and time consuming.

6. Approximately one-third of the people in Division of Mental Health and Developmental Disability funded programs in Anchorage are from outside the southcentral region. Eight of ten children living at Our Lady of Compassion Care Center are also from outside the region.

7. In compliance with P.L. 100-203 (OBRA, Nursing Home Reforms), Alaska is moving some residents of nursing homes who experience developmental disabilities to community residential settings. The federal government, through the Medicaid program, pays 50% of the cost of care in nursing homes. The state will be required to pay 100% of the cost of community based care for these same individuals. Many other states will be able to recover 50% of the cost of community placements for nursing home residents from the federal government through the use of Medicaid waivers.

CRITICAL ISSUES	RECOMMENDATIONS
1. The role of agencies and service providers is changing. In Alaska and nationally, consumers are advocating for service philosophies that recognize and include consumers and families at all levels of descision making.	1. Service agencies need to be aware of their changing role of being a facilitator and helper rather than a decision maker and director.
2. Young adults who finish high school often wait years before finding residential support or employment through community programs.	2. The Division of Mental Health and Developmental Disabilities, the Division of Vocational Rehabilitation and the Department of Education should form a group to annually plan for the residential support and employment needs of young people graduating from or finishing high school. The work of this group should also include developing new funding mechanisms and methods of simplifying the movement from one system to another.

Public Testimony Related to Item #2

"I have always been convinced that Alaska was the best place I knew for raising a handicapped child. That is still true. But now that she is about to become an adult, I see the opportunities for her dwindling. If Alaska is among the top states for education of the developmentally disabled, as we know it is, where do these people go when they become adults?" (Fairbanks Parent)

"I think that one thing that the state has to look at is that the millions of dollars they are spending on educating special education students until they are 21 is wasted if at age 21 children like my son have nowhere to go. Right now he has nowhere to go." (Chugiak Parent)

3.	Alaska's community programs are generally of high quality but without state standards, there is no state assurance of the protection of the rights of consumers. The state has a responsibility to oversee the quality of the programs it funds.	3. The Division of Mental Health and Developmental Disabilities should immediately begin an evaluation period for standards developed during F89 for services funded by the division. The state and service providers have an opportunity to work together to implement standards that will protect consumers. The evaluation period should include on-site monitoring by the division.
4.	There is currently no systematic method of dealing with the DMHDD waiting list. People who are new to the list, but in crisis, are often the first to find placements. Residents of nursing homes and Harborview who are on the waiting list are often not considered for placements in community based programs. Likewise, people who live in community settings and who are ready to move to less restrictive settings are often unable to find appropriate placements.	4. The Division of Mental Health and Developmental Disabilities should develop a method for dealing with the waiting list which includes a process which provides a systematic method of access to services for first time consumers of services, people in crisis, those in programs looking for other settings, and people currently residing at Harborview Developmental Center and in nursing homes.

Public Testimony Related to Item #4

"Here in the Valley, we have what I would label a critical situation, in terms of the number of people going without services. We are only able to serve less than one out of every three people who need residential and vocational services." (Wasilla Service Provider)

"I want people to remember that, when they look at waiting lists, that these are not numbers, these are people. It's everyday quality of life that is suffering." (Anchorage Parent)

5.	There is great disparity in eligibility criteria for programs serving people who experience disabilities. As a person ages, the services and supports they can receive change. A child is eligible for medical services that are not available to adults. Adults do not have access to the therapy services that children receive as part of special education. Another area of confusion is that some services, especially special education, are entitlement programs. Once a child finishes school, the state is no longer required to provide services.	5. The Division of Mental Health and Developmental Disabilities should change the state definition of developmental disability to the functional definition to be consistent with current federal legislation. Also, agencies need to consider the organization of their services, and how this can sometimes lead to delays in service and repetitive eligibility processes, from a consumer point of view.

Public Testimony Related to Item #5

"There is no guarantee that we will continue to receive respite care or residential services next year. As a parent, this is kind of a nightmare for me. It leaves me not knowing what my daughter's future is going to be, what's going to happen to her when I become old." (Soldotna Parent)

6.	Planning for a "service system" is impossible with current methods of data collection. Information collected by individual programs about the people they serve is generally not comparable across programs. The majority of people probably use more than one service at a time but it is currently not possible to determine how people use the "system" to meet their needs.	6. The state should require that all new agency information systems use a common system of generating consumer identifiers. This will greatly enhance the state's ability to compare information across programs.

7.	The range of services people who experience disabilities in Alaska receive is largely dependent on where they live. People living in the state's rural areas often must leave family and culture hundreds of miles behind to move to urban areas for services they need.	7.	State agencies should continue efforts towards regionalization so that consumers are not required to move out of their region to acquire services. All new service development should be a partnership between the state and the local community and should provide culturally appropriate services and community and individual empowerment.

Public Testimony Related to Item #7

"In some areas, the waiting lists are so long and the services so scarce that many people have given up hope." (Anchorage Parent)

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Diane Preston
Joy Price
Barbara Raetsch
Gerald Rafson
Jerry Schack
Candace Shannon
Jerry Swartz
Betty Taaffe
Rick Tessandore
Carl Thorkildsen
Dorothy Truran
Rose Vaughn
Jack Walker
Nancy Witte
Leslie Yamamoto

GLENALLEN

Bill Burwell

HOMER

Jeremy Beach
Joyanna Geisler
Erin Griffen
Shara Knapp
Lucy McKinney
Cheryl Mortimer

JUNEAU

John Carney
Rosie Peterson
Mike Renfro
Sue Roth
Donald Snowhook
Linda Spurlin

KAKE

Susan Hall

KENAI

Sylvia Anastay
Karen Anderson
Carol Baker
Cindy Derning
Melissa Frates
Dave Goodrich
Brenda Jager
Jim Kamph
Heidi Priest
Carol Smith
Jeannette Sorrels
Teresa Younger

KETCHIKAN

Brynn Bolling
Bess Clark
Dick Clevenger
Marilyn Conely
Joanna DeSanto
Bob Gore
Ron Hamberger
Jane Hanchett
John Harrington
Judi Loden
Bonne Makinson
Patty Mullins
D.J. O'Brien
Sue Stone
Denny Terry
Bett Union-Jakubek
Pat Weimer

KIANA

Rudy Black

KLAWOCK

Brenda Trumble

KODIAK

Penelope Goforth

KOTZEBUE

Dave Baum
Esther Curtis
Laurie Delisle
Mark Delisle
Clyde Farrington
Stella Hensley
Lulu Hunnicutt
Elaine Lachlan
Arlys Loew
Angie Rawls
Mike Rawls
Lorraine Russell
Marie Saterlee
Dolly Sours

NENANA

Nancy Bayer
Terry Rovig

NIKISKI

Colleen Pillon
Dan Pillon
Debbie Yanak
John Yanak

PALMER

Ted Bielman
John Bitney
Gay Crozer-Woody
Bim Hoylman
Amon Kelly
Rep. Ron Larson
Roy Lee Samuels

QUINHAGAK

Christine Hunter
Elizabeth Hunter

SEATTLE

Gina Gross

SELAWIK

Violet Cleveland
Marie Savok
Ramona Sheldon
Edith Snyder

SHISHMAREF

Marilyn Goodhope

SITKA

Bruce Anderson
Roger Brobst
Sid Cowan
Bertha Karras
Marge Mochak

SOLDOTNA

Alex Boatwright
Trish DeBusschere
Dennis Haas
Lynette Haas
Shawn Harrison-Hawbold
Mary-Ellen Johnson
Maureen Karigan
Marta Kriner
Roger Leibner
Lourdes Link
Fritz Miller
Dennis Murray
Shelley O'Guinn
Judy Reis
Mary Rubadeau
Nancy Schaafsma
Robert Schaafsma
Rose Sheare
Judi Walgenbach

TALKEETNA

Edith Adams
Jim Adams

TUNUNAK

Louise Kanrilak
Mark Kanrilak

VALDEZ

Alison Anderson
Florence Bandolin
Sue Brady
Laura Delacruz
Janis Johnson
Mildred Kiser
Jan Michaud
John Piper
Mary Rogers
Axel Schmetzte
Arlene Spaulding

WASILLA

Beverly Bailey
Sheri Brody
John Cannon
Sharon Cannon
Bonnie Jo Darnell
Cliff Forney
Kip Harding
Duncan Hunter
Dawn Jorgenson
Joanne Kessler
Jean KinKaid
Rep. Curt Menard
Debbie Myers
Sandra Pugh
Diana Reinhart
Iola Robinson
Joyce Semonin
Fred Shor
Patricia Walter
Linda Marie Weintraum